Doctoral theses at NTNU, 2022:315

Annette van der Meer Halvorsen

Living with spinal cord injury

Doctoral thesis

NTNU
Norwegian University of Science and Technology
Thesis for the Degree of
Philosophiae Doctor
Faculty of Medicine and Health Sciences
Department of Public Health and Nursing

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Norwegian University of
Science and Technology

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Trondheim, October 2022

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ISBN 978-82-326-5787-2 (printed ver.)
ISBN 978-82-326-5673-8 (electronic ver.)
ISSN 1503-8181 (printed ver.)
ISSN 2703-8084 (online ver.)

Doctoral theses at NTNU, 2022:315

Printed by NTNU Grafisk senter

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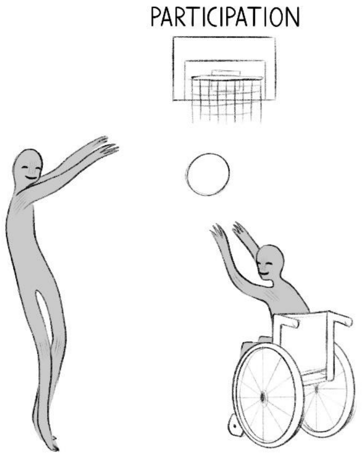


Å leve med ryggmargsskad(d)e

En skade i ryggmargen, for eksempel etter ulykke eller sykdom, oppstår relativt sjeldent, men har omfattende konsekvenser som påvirker store deler av kroppen. De fleste ryggmargsskader fører til lammelser og tap av følelse nedenfor skadestedet, med nedsatt blære-, tarm- og seksualfunksjon. Denne ph.d.-avhandlingen undersøker gjennom tre studier, hvordan det går med pasienter og deres pårørende i årene etter en ryggmargsskade.

For mennesker som var i jobb før ryggmargsskaden kan det være utfordrende å komme tilbake til arbeidslivet etter skaden. Vi benyttet data fra Norsk ryggmargsskaderegister (NorSCIR) koblet til registerdata fra SSB og NAV for å følge arbeidsdeltakelse og trygdeytelser i opptil 6 år etter skaden for 451 personer med ryggmargsskade, og sammenlignet med en matched gruppe på 1791 personer (uten skade) fra den generelle norske befolkningen. Vi fant at en ryggmargsskade reduserte arbeidsdeltakelsen betydelig; seks år etter skaden hadde 63% av personene med ryggmargsskade noe inntekt fra arbeid sammenlignet med 91% blant personene i sammenligningsgruppa. Mer enn halvparten av personene med ryggmargsskade som hadde inntekt fra arbeid, mottok samtidig trygdeytelser i form av sykepenger, arbeidsavklaringspenger eller uføretrygd.

For de fleste mennesker er det viktig å ha en arbeidsplass, å delta i fritidsaktiviteter, samt å ha gode relasjoner med andre mennesker. For personer som lever med ryggmargsskade kan det være utfordrende å delta i slike aktiviteter. Gjennom et spørreskjema, som ble sendt til personer med ryggmargsskade registrert i NorSCIR, undersøkte vi ulike sider ved dagliglivet, som deltakelse i ulike aktiviteter og livskvalitet. Av de 339 deltakerne oppga halvparten å ha god eller svært god livskvalitet. Det var sterk sammenheng mellom å erfare aktiv deltakelse på ulike arenaer og tilfredshet med livet og mental helse. Utover ryggmargsskadens alvorlighetsgrad var faktorer som familieinntekt og utdanning av stor betydning for deltakelse og livskvalitet.

Syttitre pårørende til personer med ryggmargsskade deltok i en spørreundersøkelse som kartla ulike sider ved dagliglivet, omsorgsbyrden, deltakelse og livskvalitet. De aller fleste hadde det bra på de ulike områdene. Alle syntes det var viktig å bry seg, og de fleste var glade for å gi omsorg. Likevel rapporterte en fjerdedel høy omsorgsbelastning, spesielt knyttet til emosjonelle tilpasninger. Mest utsatt for høy omsorgsbelastning var pårørende i yrkesaktiv alder og de med middels utdanning (fullført videregående skole).

Oppsummerende viser denne avhandlingen at det er stor variasjon i hvordan personer med en ryggmargsskade og deres pårørende opplever ulike livsområder etter skaden, men også at de fleste har det bra.

Annette van der Meer Halvorsen
Institutt for samfunnsmedisin og sykepleie
Hovedveileder: Professor Aslak Steinsbekk
Biveiledere: Førsteamanuensis Kristine Pape, professor Marcel Post og professor Fin Biering-Sørensen.
Finansieringskilder: Stiftelsen Dam, Samarbeidsorganet Helse Midt-Norge og NTNU, og Felles forskningsutvalg St Olavs hospital og Fakultet for medisin og helsevitenskap

Ovennevnte avhandling er funnet verdig til å forsvares offentlig
for graden ph.d. i Medisin og Helsevitenskap
Disputas finner sted i Seminarrom MTS11, Fred Kavli-Bygget, NTNU
Mandag 31. oktober 2022, kl. 12.15

Table of contents

Acknowledgments

I highly acknowledge the funders of this PhD project:

- 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 (Grant number 18/420).
- The joint research committee between St. Olav's hospital HF and the Faculty of Medicine and Health Sciences at the Norwegian University of Science and Technology (Grant number 2018/42795).

Many persons have been involved in this PhD project; I express my sincere thanks to all who have helped, supported, and encouraged me in different ways during the different phases of this project! There are a number of people I would like to thank in particular.

I thank all the persons with SCI and their next of kin who participated in the studies. This work would not have been possible without your contributions!

The multidisciplinary approach to the project, with a research team that included four supervisors and three user representatives, was invaluable and inspiring.
I express my sincere gratitude to the following for their contributions to this research project:

- Professor Aslak Steinsbekk, my main supervisor, for believing in me, for sharing your knowledge and expertise, for teaching me scientific writing, for focussing on user-involvement, for your enthusiasm, and for always taking the time to answer my questions. I could not have had better supervision throughout this work!
- Kristine Pape, PhD MD, my co-supervisor, for helping me write all the applications needed for the data delivery from SSB and NAV, for teaching me to use STATA, for helping with preparing the data files and running the analyses, and - last but not least - for helping me critically interpret the results.
- Professor Marcel Post, my co-supervisor, for your encouragement, support, and patience. Your overview in the field, clear thoughts, (Dutch) wisdom, and inspiring comments were invaluable to me.
- Professor Fin Biering-Sørensen, my co-supervisor, for being my inspiration as a physician in the clinical field and in research. Your knowledge, accuracy, availability, and quick responses are admirable.

- Monica Engelsjord, Steinar Mikalsen, and Anders Nupen Hansen, my other members of this research team, who used their personal experience to provide input to all steps in this project, from the study design to reporting the results. Thank you for your valuable contributions.

I thank the current (and past) leaders at St Olav's hospital: Ragna Elise Govatsmark, Hild Fjærtoft, Johan Fredrik Skomsvoll, Sigmund Gismervik, Bjørn Skogstad, and Vigdis Strand. They made it possible for me to combine hospital work with my research at the Department of Public Health and Nursing at the NTNU.

Thanks to my friends and colleagues at the department of Medical Quality Registries for your support, and particularly to my colleague and friend, Ann Louise Pettersen, for being patient with my leave of absence, and for all the fantastic work you are doing for the Norwegian and Nordic SCI registries.

Thanks to my friends and colleagues at the Clinic of Physical Medicine and Rehabilitation, especially at the SCI unit. Tom Tørhaug and Sara Langlo: I am looking forward to joining you again! As a young resident in Physical and Rehabilitation Medicine, Erik Sigurdsen introduced me to the field of SCI care. His dedication for this patient group still inspires me. Thanks to Toril Skandsen, Berit Brurok and Sofie Nyland Engelstad for your support, and to Annelie Schedin Leiulfsrud for contributing as co-author.

Furthermore, I would like to thank the members of the Research Group for Patients Education and Participation and the Work and Health Research Group - both at the Department of Public Health at Nursing, NTNU - for many fruitful meetings.

I am very grateful for all practical help. Linda Åsheim, thank you being my contact person in The Norwegian Association of Disabled. Thanks are due to Albert Verhagen, Ingrid Riphagen, Wilma van de Veen, and Lars Halvorsen for their contribution in the translations. Thanks to Janou Hemsing-Salden for help with English communication.
Thanks to Kristel Svenning for your assistance with the economic affairs. Thanks to Eilev Hagen, for technical assistance during the data collection in eFORSK. Thank you Juni Pape for the nice illustrations you made for this thesis.

I further thank the members of the steering committee for the Norwegian and Nordic SCI registries for your support. Thanks to my colleagues Ingeborg Beate Lidal and “PhD sister” Ingebjørg Irgens at Sunnaas hospital, for kindly answering my questions.

I owe great thanks to all my dear friends in Norway and the Netherlands, for being supportive and for invaluable friendships.

Finally, last but not least, I will express my love and thankfulness to my family.
I thank my parents for giving me the very best prerequisites to develop, and for sharing their passion for medicine. Thank you for always encouraging me. And thanks to my parents-in-law for always being there.

Special thanks to my dear husband Lars, for his caring support, always being positive, and for being you! Thanks to our wonderful children, Tristan and Nora. Your passion, motivation, and goal-oriented hard work in sports are impressive, and provided me the strength to complete this work. Lars, Tristan, and Nora, you are the love and joy of my life.

Trondheim, May 2022
Annette van der Meer Halvorsen

List of papers

Paper 1:

Annette Halvorsen, Aslak Steinsbekk, Annelie Schedin Leiulfsrud, Marcel W. M. Post, Fin Biering-Sørensen, Kristine Pape.

Labour market participation after spinal cord injury. A register based cohort study.

Submitted to Spinal Cord, April 2022

Paper 2:

Annette Halvorsen, Kristine Pape, Marcel W. M. Post, Fin Biering-Sørensen, Steinar Mikalsen, Anders Nupen Hansen, Aslak Steinsbekk.

Participation and quality of life in persons living with spinal cord injury in Norway.

J Rehabil Med. 2021 Jul 15;53(7):jrm00217. doi: 10.2340/16501977-2858. PMID: 34232321; PMCID: PMC8638721.

Paper 3:

Annette Halvorsen, Kristine Pape, Marcel W. M. Post, Fin Biering-Sørensen, Monica Engelsjord, Aslak Steinsbekk.

Caregiving, participation, and quality of life of closest next of kin of persons living with Spinal Cord Injury in Norway.

J Rehabil Med. 2022 Apr 7;54:jrm00278. doi: 10.2340/jrm.v54.2162. PMID: 35266007

Abbreviations

AIS	American Spinal Injury Association Impairment Scale
ASIA	American Spinal Injury Association
CSI	Caregiver Strain Index
GEE	Generalized Estimating Equations
HRQoL	Health Related Quality of Life
ICF	International Classification of Functioning, Disability, and Health
InSCI	The International Spinal Cord Injury Community survey
ISNCSCI	International Standards for Neurological Classification of Spinal Cord Injury
MHI-5	Mental Health subscale of the Medical Outcomes Study Short Form Health Survey
NAV	Norwegian Labour and Welfare Administration
NorSCIR	Norwegian Spinal Cord Injury Registry
NTSCI	Non-Traumatic Spinal Cord Injury
SCI	Spinal Cord Injury
SSB	Statistics Norway
TSCI	Traumatic Spinal Cord Injury
OECD	The Organisation for Economic Co-operation and Development
PRM	Physical and Rehabilitation Medicine
QoL	Quality of Life
SRB	Self-rated burden
USER-P	Utrecht Scale for Evaluation of Rehabilitation-Participation instrument
WHO	The World Health Organization
WHOQoL-5	World Health Organization Quality of life assessment-BREF, five items

Summary

This thesis consists of three studies about living with spinal cord injury (SCI) among persons with SCI and their next of kin. SCI often results in severe physical impairments and limitations, which impact all aspects of life. The onset of SCI not only drastically disrupts the lives of affected patients but also of their next of kin. The overall aim of this thesis was to provide new knowledge about living with SCI, specifically on participation, quality of life (QoL), and caregiving, among persons with SCI and their next of kin.

Study 1 aimed to investigate labour market participation following SCI compared to a matched sample from the general population, and to describe the impact of personal and SCI characteristics on labour market participation.

A cohort study was conducted including 451 persons with SCI identified from the Norwegian SCI Registry (NorSCIR) who had income from work in the year before the injury, and a matched control group of 1791 persons taken from the general Norwegian population. Longitudinal data on the period between one year before injury and up to six years after injury were analysed, using Norwegian population registry data on employment (defined as receiving any amount of pay for work), education, income, and sickness and disability benefits. We observed that SCI substantially decreased labour market participation up to six years after injury (from 100% to 63%) compared to the general population (from 100% to 91%), especially among the more severely injured and low-educated persons with SCI. Even if a relatively large proportion of patients with SCI remained in some degree of work activity, more than half did so in combination with receiving benefits. Patients with SCI with lower severity of neurological outcomes, higher level of education, younger age at injury, and a stronger pre-injury attachment to employment were more likely to have higher labour market participation.

Study 2 aimed to describe the association between sociodemographic and SCI characteristics, of people living with SCI, and participation and QoL, and to study the association between participation and QoL in this group of people.

In this study, persons registered in the NorSCIR between 2011 and 2017 were invited to participate in a survey performed in 2019. Of the 651 individuals invited to complete the follow up survey, 339 participated. The questionnaire contained questions about daily life,

participation, life satisfaction, and mental health. Data from the survey were linked to clinical data on SCI characteristics from NorSCIR. We observed that sociodemographic factors, such as family income and education, were found to have a greater impact on QoL and participation, than the severity of the injury itself. Participants who reported to be currently working as their main activity and had high family income had higher scores on all measures of participation and QoL compared to those who were not working and had lower income. Participation was strongly associated with life satisfaction and mental health.

Study 3 aimed to investigate how next of kin of persons with SCI experience various life areas in terms of caregiving, participation, and QoL, and the impact of personal characteristics of next of kin and SCI characteristics.

A survey among 73 next of kin for persons with SCI was performed in 2019-2020. The questionnaire contained questions about daily life, caregiving, participation, life satisfaction, and mental health. Data from the survey were linked to clinical data on SCI characteristics from NorSCIR. We observed that the majority of caregivers of persons living with SCI in Norway are doing well in most life areas. Three out of four caregivers reported good mental health and life satisfaction. All participants considered it important to care and most were happy to do so. Nevertheless, one-quarter of the next of kin reported high levels of strain, especially related to emotional adjustments. Most at risk for caregiver strain were participants of working age and those with secondary education

Together, these studies contribute to scientific knowledge regarding participation, QoL, and caregiving among persons with SCI and their next of kin, especially those living in Norway. The studies in this thesis showed a great variation in how persons with SCI and next of kin report their experiences in different life areas in the first eight years after injury. A large part of persons with SCI and their next of kin are doing well. However, some patients and next of kin groups are at risk for poor outcomes. To support the everyday life of persons with SCI and their next of kin, the SCI rehabilitation team should (besides health interventions) focus on vocational rehabilitation, environmental adaptations, and social and emotional support in a lifelong perspective.

1 Background

This thesis is about living with SCI from the perspectives of persons with SCI and their next of kin. SCI is a severe physical disability, and the need for more knowledge about its consequences was the driving force behind this work.

During acute care and post-acute rehabilitation of persons having suffered SCI the main focus is on medical problems and physical challenges. In the research literature there is increasing attention on the adjustment to living with SCI, but less is known about the situation in Norway. This lack of knowledge motivated me to search for new knowledge on how persons with SCI and their next of kin manage after the injury in terms of participation, QoL, and caregiving.

1.1 Living with disability

Over 1 billion people live with a disability worldwide (World Health Organization & World Bank, 2011). Disability is defined by the United Nations Convention on the Rights of Persons with Disabilities as long-term physical, mental, intellectual, or sensory impairments, which in interaction with various barriers may hinder a person's full and effective participation in society on an equal basis with others (United Nations, 2007).

Disability is part of human life because almost everyone will be temporarily or permanently impaired at some point in life (World Health Organization & World Bank, 2011). Persons who reach old age will experience increasing difficulties in functioning. Most extended families have a member with disabilities, and many non-disabled people take responsibility for supporting and caring for their next of kin and friends with disabilities (World Health Organization & World Bank, 2011).

Adjusting to living with a sudden onset of disability can be a difficult transition because people have to learn to cope with limitations, overcome challenges, and rebuild a rewarding life. People with disabilities often experience various barriers (attitudinal, environmental, and institutional), which hamper participation (Rohwerder, 2015).

1.1.1 Medical, social, and biopsychosocial models of disability

There is a spectrum of conceptual models of disability, and the development of these models took place concomitantly with the general development of ideas and concepts on health; they

influenced – and, in turn, were influenced by – the social setting to which they belonged (Masala & Petretto, 2008).
Two categories stand at the ends of the spectrum: the “Medical” models, in which disability is seen as an attribute of a particular health condition, and the “Social” models, in which disability is a product of the environment (Petasis, 2019).

Historically, disease was seen as related to pathology and thus treated by medical means. Attitudes towards disability and loss of functioning have, however, changed over time, resulting in the development of social models in recent decades (Petasis, 2019). Social models frame disability not as an underlying medical condition or pathology but instead as secondary to the social, legislative, and attitudinal environment in which the person lives. This environment, at least the man-made environment, have typically been created or designed to suit the needs of the average healthy human being.

The medical model and the social model are often presented as dichotomous. However, at least in rehabilitation, disability is not seen as strictly medical or purely social. Rather, the “biopsychosocial” model prevails (Petasis, 2019). In this model disability is seen as a result of the individual-environment interaction. The World Health Organization (WHO) International Classification of Functioning, Disability, and Health (ICF) is an example of a biopsychosocial model of disability (World Health Organization, 2001).

1.1.2 The International Classification of Functioning, Disability, and Health (ICF model)

The ICF model is the biopsychosocial model of disability (Figure 1) officially endorsed by all 191 WHO Member States in the Fifty-fourth World Health Assembly on 22 May 2001 as the international standard to describe and measure health and disability (World Health Organization, 2001). It is based on an integration of the social and medical models of disability, and serves as a worldwide common language of rehabilitation (World Health Organization, 2002).

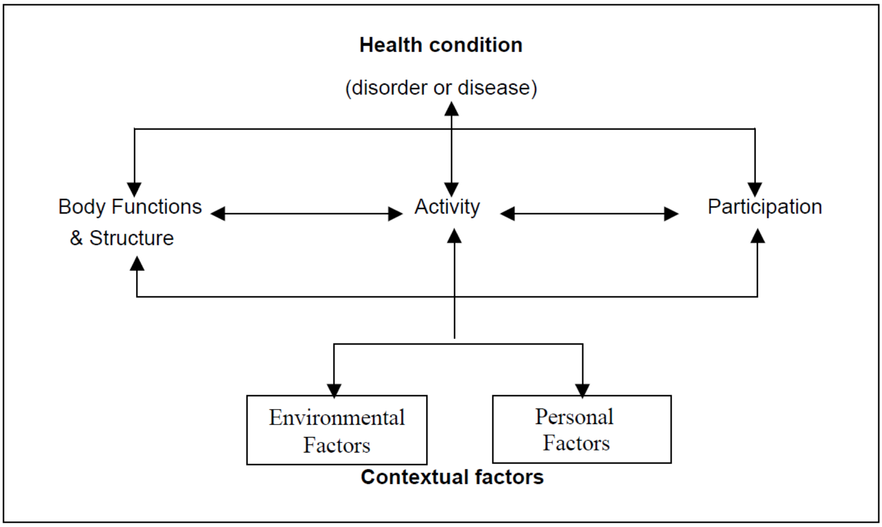


Figure 1. The International Classification of Functioning, Disability, and Health model (World Health Organization, 2002)

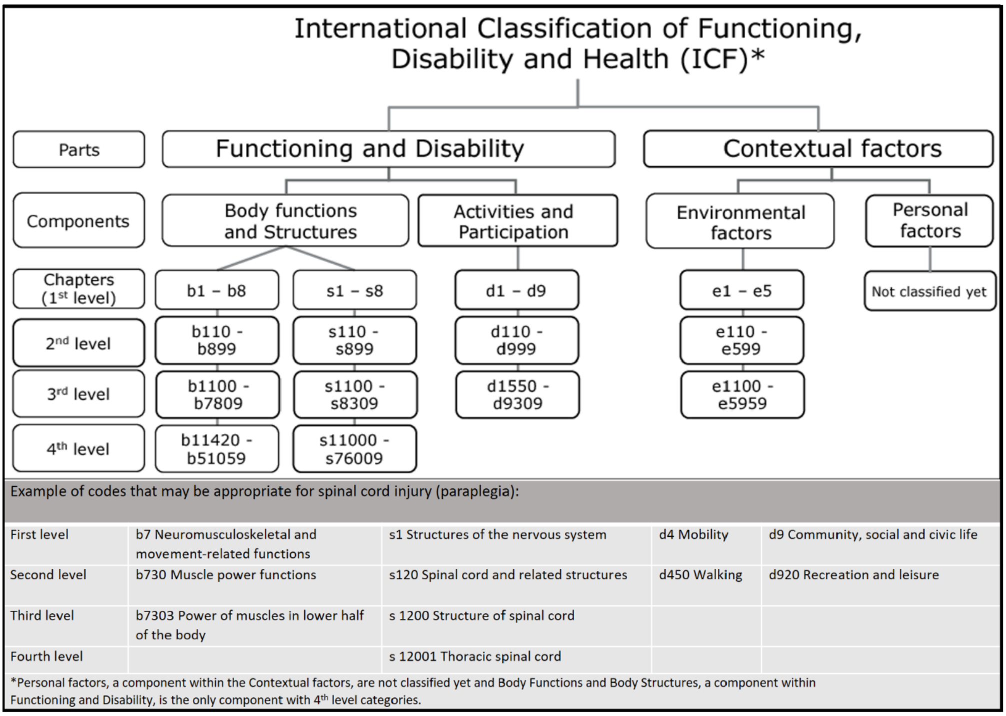
The ICF conceptualises a person's level of functioning as a dynamic interaction between her or his health conditions, environmental factors, and personal factors. The ICF model identifies human functioning at three levels (World Health Organization, 2001):

1) The body functions and structures of people, and impairments thereof. (Functioning at the level of the body.)
2) The activities of people and the activity limitations they experience. (Functioning at the level of the individual.)
3) The participation or involvement of people in all areas of life and the participation restrictions they experience. (Functioning of a person as a member of society.)

These levels are influenced by contextual factors, which are divided into personal factors (such as age, history, and psychological characteristics) and environmental factors (such as social support or financial and economic resources). All these aspects interact with each other.

Functioning is, in the ICF model, an umbrella term for body functions, body structures, and activities and participation. It is viewed as the result of the interaction of a health condition and personal and environmental factors. Disability, on the other hand, is in the ICF model, the umbrella term for impaired body functions and structures, activity limitations, and participation restrictions. It is viewed as the negative aspects of interaction with a health condition and personal and environmental factors.

The ICF is a framework and classification system that can be used to assess the functioning of an individual. Qualifiers are used to record the extent of functioning or disability in a domain or category, or the extent to which an environmental factor is a facilitator or barrier (World Health Organization, 2001). ICF categories are arranged in a stem-branch-leaf structure within each component, in which the more detailed level categories share the same attributes as the broader level categories (Figure 2). Examples of this are given in figure 2.



Example of codes that may be appropriate for spinal cord injury (paraplegia):

First level	b7 Neuromusculoskeletal and movement-related functions	s1 Structures of the nervous system	d4 Mobility	d9 Community, social and civic life
Second level	b730 Muscle power functions	s120 Spinal cord and related structures	d450 Walking	d920 Recreation and leisure
Third level	b7303 Power of muscles in lower half of the body	s 1200 Structure of spinal cord		
Fourth level		s 12001 Thoracic spinal cord		

*Personal factors, a component within the Contextual factors, are not classified yet and Body Functions and Body Structures, a component within Functioning and Disability, is the only component with 4th level categories.

Figure 2. Components and classification trees of the International Classification of Functioning, Disability, and Health (ICF) (World Health Organization, 2001), with examples of codes that can be relevant for persons with SCI.

1.2 Spinal cord injury

1.2.1 The spinal cord

The spinal cord is a part of the central nervous system and is situated within the spinal column, also known as the vertebral column. The collection of nerves at the end of the spinal cord is known as the cauda equina, due to its resemblance to a horse's tail. The spinal cord ends at the upper portion of the lumbar (lower back) spine (Figure 3).

The spinal cord is divided into four different regions (cervical (C), thoracic (T), lumbar (L), and sacral (S)) and is organized into 31 segments, defined by 31 pairs of nerves exiting the cord. The spinal nerves are the major nerves within the peripheral nervous system and support functioning of the body. They carry motor, sensory, and autonomic signals between the spinal cord and the body (Kirshblum & Campagnolo, 2011).

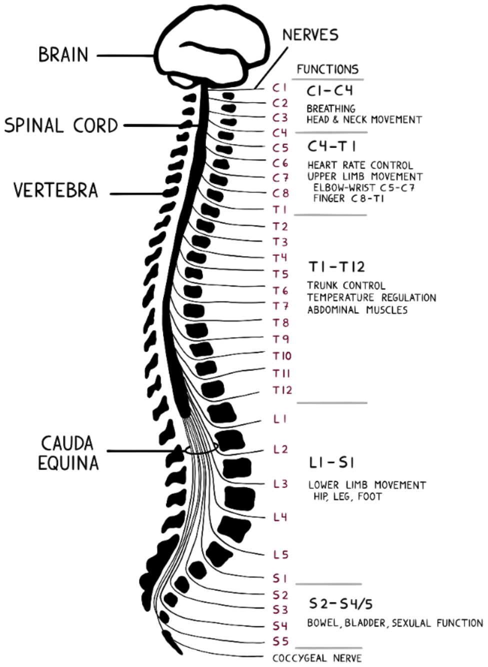


Figure 3. The spinal cord and the spinal nerve functions.

(Illustration by Juni Pape)

The spinal cord and brain make up the central nervous system. The spinal cord is the main pathway for information connecting the brain and the peripheral nervous system and plays a vital role in various aspects of the body's functioning (Kirshblum & Campagnolo, 2011). The three major functions of the spinal cord are:

1) Carrying signals from the brain: The spinal cord receives nerve signals from the brain that control movement (motor signals) and autonomic functions (refers to the reflex actions that your brain controls without you having to think about it; e.g., blood pressure).
2) Carrying information to the brain: The spinal cord nerves also transmit messages in the reverse direction, from the body to the brain, such as sensations of touch, pressure, and pain (sensory signals).
3) Acting as a centre for coordinating many reflexes.

1.2.2 What is spinal cord injury?

SCI is defined as impairment of the spinal cord or cauda equina resulting from the application of an external force of any magnitude or a dysfunction or disease process, resulting in temporary or permanent impairment in its normal motor, sensory, or autonomic function (Biering-Sorensen et al., 2017).

SCI is divided into traumatic and non-traumatic aetiologies. Traumatic SCI (TSCI) occurs when an external force (for example, road traffic injuries, fall, sports-related injuries, or violence) acutely damages the spinal cord. Non-traumatic SCI (NTSCI) occurs when an acute or chronic disease process, such as infectious disease, tumour, vascular disease, or degenerative disc disease, generates the primary injury.

SCI causes an interruption in the neurological pathway and affects conduction of sensory and motor signals across the site(s) of lesion(s), as well as the autonomic nervous system (Kirshblum et al., 2011). Thus, this interruption results in muscle weakness and loss of sensation below the level of the lesion, as well as autonomic dysfunction resulting in multiple impairments such as loss of bowel, bladder, and sexual functions. SCI can lead to lifelong disability.

Persons with SCI are at risk for secondary complications such as pressure sores, urinary tract infections, deep vein thrombosis, respiratory complications, autonomic dysregulation, pain and spasticity. This can occur in both the acute phase as well long term.

Persons with SCI face several challenges in their everyday lives. The onset of an SCI requires, in addition to physical adjustments, tremendous psychological adjustments (Chhabra, 2015). Support from family, friends, professionals, and society represents an important resource to meet these challenges. Since persons with SCI are confronted with all kinds of short- and long-term consequences and complications, lifelong care for persons with SCI living in the community is needed (Bloemen-Vrencken et al., 2005). Furthermore, an important transition in the continuum of care occurs when individuals return to community living. The focus shifts from the medical management of the injury to providing social services that help people resume daily activities and valued social roles (Noreau et al., 2013). Having a SCI changes some things forever, but it is still possible to have a fulfilling life (Bickenbach, 2013).

The founder of the modern treatment of SCI, Sir Ludwig Guttmann, said: “Spinal cord paralysis is not the end of life; it is the beginning of a new life”.

1.2.3 Epidemiology of spinal cord injury

The incidence, prevalence, and causation of SCI differs between developing and developed countries. The global incidence rate (new cases) of SCI is estimated between 40 and 80 new cases per million population (all causes) per annum (Bickenbach, 2013). The majority of spinal cord injuries around the world are due to traumatic causes (motor vehicle crashes and falls), though the proportion of non-traumatic SCI (tumours and degenerative conditions) appears to be growing (Bickenbach, 2013).

There are currently no reliable global estimates for the prevalence of persons who live with SCI (Bickenbach, 2013). Traumatic SCI prevalence rates range from 280 to 1298 per million (Bickenbach, 2013). Prevalence data for non-traumatic SCI are only available for Australia (New et al., 2013) and Canada (Noonan et al., 2012), which are 367 and 1227 per million, respectively.

The mean age of patients with SCI has gradually increased. The proportion of persons with TSCI in Nordic countries in the age-group 60+ years increased from 9% prior to 2000 to 35% in 2001–2020 (Moschovou et al., 2022). The male-to-female ratio is at least 2:1 (Bickenbach, 2013).

An epidemiological study based on traumatic SCI data from the Norwegian SCI registry (NorSCIR), during a five-year period (2012-2016), showed that the annual incidence rate was lower than what is reported internationally: 11.4- 15.9 new cases per million, with a mean age of 47 years. Falls were the main cause of traumatic SCI (Halvorsen et al., 2019a). A similar study for non-traumatic SCI in the same study period showed annual incidence rates between 7.7-10.4 new cases per million, with a mean age of 55 years (Halvorsen et al., 2019b). There were more males than females who sustained SCI in both studies.

1.2.4 Neurological outcome and classification

Neurological outcomes may vary across individuals, depending on such factors as the level and completeness of the injury (Figure 4). Generally, the higher the level of the injury to the spinal cord and the more complete, the more severe the symptoms:

- Tetraplegia refers to impairment or loss of motor and/or sensory function in the cervical segments of the spinal cord and results in impairment of function in the arms as well as typically in the trunk, legs, and pelvic organs (Kirshblum et al., 2011).
- Paraplegia refers to impairment or loss of motor and/or sensory function in the thoracic, lumbar, or sacral segments of the spinal cord. Arm functioning is intact with paraplegia, but - depending on the level of injury - the trunk, legs, and pelvic organs may be involved (Kirshblum et al., 2011).
- People who experience a complete SCI have no feeling in their anal area and cannot voluntary tighten their anus; this is defined by the loss of sensation in the lowest sacral segments, S4 and S5 (Kirshblum et al., 2011).

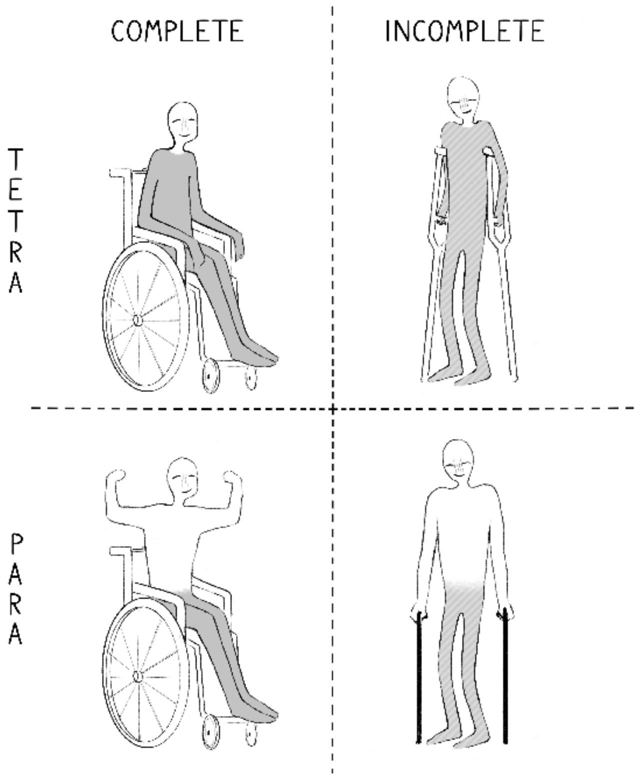


Figure 4. Neurological outcome after spinal cord injury
(Illustration by Juni Pape, adapted from Spinalis Handbook (Richard Levi & Claes Hultling, 1999))

A careful neurological assessment is important for clinical evaluation and to define the severity of injury. The International Standards for Neurological Classification of Spinal Cord Injury (ISNCSCI), published by the American Spinal Injury Association (ASIA), is a well-known international communication tool for clinicians and researchers to quantify neurological impairment after SCI (Kirshblum et al., 2011).

The ISNCSCI is based on:

- The ASIA motor score, which grades muscle strength and movement.
- The ASIA sensory score, which grades light touch and pinprick feeling.

- The neurological level of injury, which refers to the most caudal segment of the cord with intact sensation and antigravity (3 or more) muscle function strength, provided there is normal (intact) sensory and motor function rostrally, respectively.
- The ASIA Impairment Scale grade (AIS), which determines whether the injury is complete or incomplete. The AIS assigns the SCI a severity grade. Grades range from A to E, with A meaning complete and E meaning normal according to the ISNCSCI.

1.2.5 Rehabilitation after spinal cord injury

There is still no cure for SCI but treatment and rehabilitation have improved drastically. Sir Ludwig Guttmann (1899-1980) and Dr Donald Munro (1889-1973) revolutionized the management of SCI by defining the fundamentals of care and rehabilitation (Chhabra, 2015).

The WHO describes five main health strategies to achieve and maintain population health: 1) Prevention, 2) Promotion, 3) Treatment, 4) Rehabilitation, and 5) Palliative care (World Health Organization, 2010). Rehabilitation is defined by the WHO as a set of interventions designed to optimize functioning and reduce disability in individuals with health conditions in interaction with their environment (World Health Organization, 2021). It helps a child, adult, or older person to be as independent as possible in everyday activities and enables participation in education, work, recreation, and meaningful life roles such as taking care of family (World Health Organization, 2021).

Physical and Rehabilitation Medicine (PRM) applies rehabilitation as its core strategy (Stucki et al., 2007). PRM is, in contrast to other medical specialities, not defined by a disease or an organ system (Stucki et al., 2007). Instead, PRM focuses on limitations of functioning and disability associated with health conditions and the complex interaction with personal factors and the environment, according the ICF model. Rehabilitation interventions can be described as approaches to assess functioning, to optimize a person's capacity, to strengthen a person's resources, to provide a facilitative environment, to develop a person's performance, and to enhance a person's QoL (Gutenbrunner & Nugraha, 2019). Thus, rehabilitation is multidimensional: health interventions must also include social support, environmental adaptations, and psychological empowerment strategies (Gutenbrunner & Nugraha, 2019). There is strong evidence of a need for scaling up and strengthening rehabilitation due to global population ageing and an increasing incidence of chronic conditions (e.g., cardiovascular and chronic respiratory diseases, cancer, and SCI) (Stucki et al., 2018).

Four phases of SCI care may be distinguished in Norway: pre-hospital management, acute care hospital, post-acute rehabilitation (primary rehabilitation), and long-term rehabilitation (lifelong follow-up). In 1995 the ministry of Social and Health Services decided to centralise the post-acute rehabilitation and follow-up of SCI patients in Norway to three specialised centres: Haukeland University Hospital in Bergen, St. Olav's University Hospital in Trondheim, and Sunnaas Rehabilitation Hospital in Oslo/Nesodden (Statens helsetilsyn, 1998). SCI patients (traumatic and non-traumatic) are transferred to one of the three specialized centres for rehabilitation after pre-hospital management, acute care, and stabilization. A description of Norwegian SCI care, including the patients' journey through the chain of care, was previously published (Strom et al., 2017).

The three Norwegian SCI units have well-trained multidisciplinary rehabilitation teams that may include physiotherapists, occupational therapists, social workers, psychologists, teachers, sports therapists, peer support specialists, nurses, and medical doctors (Strom et al., 2017). The multidisciplinary approach during the acute, subacute, and chronic phases after injury is essential in helping individuals with SCI reach their physical, social, emotional, recreational, vocational, and functional potential. All three Norwegian SCI units offer life-long follow-up for persons with SCI. After primary rehabilitation, the patients are admitted for regular check-ups depending on their needs. Some patients have additional admission(s) at other rehabilitation institutions and/or at one of the health sports centres.

The Norwegian Spinal Cord Injuries Association (LARS) is a very active organisation of and for people with spinal cord injuries, their relatives, professionals, and others (www.lars.no). LARS organises activities and conferences for its members and is run voluntarily by members with spinal cord injuries. There are also other organised activities outside the health care system, e.g., "Active rehabilitation camps" and courses organized by the Sunnaas Foundation (a private non-profit foundation).

1.3 Experience of living with spinal cord injury

Historically, SCI has been associated with very high mortality rates and research on the outcomes after SCI has mainly focused on the survival and medical consequences in the acute phase. Life expectancy in individuals with SCI has, however, increased due to improvement in medical care (Savic et al., 2017).

In the last decades there has been a shift of research interest towards gaining a better understanding of the impact of SCI on the long-term physical and psychosocial consequences for the patient, as well as the environmental barriers they experience. The number of hits per year on PubMed with a general search by using the mesh terms “Spinal Cord Injuries” and “Quality of life” (2 hits in 1977 and 129 hits in 2021) reflects this development in interest (Figure 5).

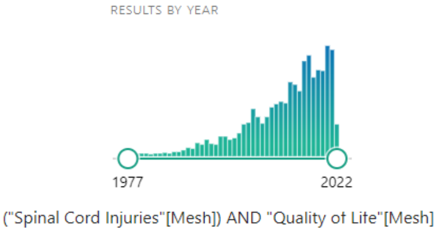


Figure 5. The number of hits per year on PubMed with a general search by using the mesh terms “Spinal Cord Injuries” and “Quality of life”.

The important role of employment among persons with SCI was first recognized in 1959 (Guttmann, 1959). Publications on the impact of SCI on next of kin were published even later (Hart, 1981; Weitzenkamp et al., 1997).

The lived experiences of persons and families living with SCI (Baker et al., 2017; Lynch & Cahalan, 2017; Post & Noreau, 2005; van Leeuwen, Kraaijeveld, et al., 2012) has thus been widely studied. However, findings of the previously performed studies may be influenced by the environmental factors of the countries where the studies are carried out, and results are thus not always generalizable to the Norwegian population.

1.3.1 Participation

"Participation" has its roots in the Latin "parcipat" (shared in), based on "pars" (part) and "carpere" (take) (*English Dictionary*, 2022). According to the ICF, participation refers to "a multidimensional concept" that can be defined as "the person's involvement in life situations" (World Health Organization, 2001), and covers an individual's experience in life activities and social roles, for example, work, leisure activities, and involvement in the community (Perenboom & Chorus, 2003). Participation restrictions have been defined as the opposite: "problems a human may experience in involvement in life situations" (World Health Organization, 2001).

Research on issues related to participation problems among persons with SCI is still limited (Hammell, 2010). In a critical systematic review on social and community participation following SCI (Barclay et al., 2015), the authors highlighted that the samples in the reviewed studies were relatively small, that the used instruments were often developed before the introduction of the ICF, and that the use of the term participation varied. In addition, knowledge of the impact of injury characteristics on participation is still underdeveloped (Gupta et al., 2019).

The concept of participation in Norwegian society, as understood among persons with SCI, has been explored in previous qualitative research (Leiulfsrud, 2016). It showed that participation was primarily understood as associated with activity, socializing, and the freedom to live an active and everyday life. Employment was recognized as an essential factor in participating in society and for being accepted as social citizens (Leiulfsrud, 2016). This is consistent with official social policy that considers employment as an essential condition for promoting social participation and integration of disabled people into society (OECD, 2010). Another study on the value of employment for people living with SCI in Norway found that health issues, age, and whether or not available jobs were meaningful from the individual's perspective or values were seen as crucial factors in their choices to remain in or opt out of the labour market (Leiulfsrud et al., 2014). This study pointed out that better coordination among the Norwegian Labour and Welfare Administration, the medical system, and employers is needed to ensure Norwegians with SCI remain in long-term employment after their injury.

Despite many persons with SCI being motivated and able to work, their employment levels are considerably lower than in the general population across the world (Post et al., 2020). The

proportion employed following SCI in Norway was previously reported to range from 35% to 52% in different studies (Leiulfsrud et al., 2020; Lidal et al., 2009; Post et al., 2020; Solheim & Leiulfsrud, 2018). The lower 35% employment rate was found in a study sample (N=165) consisting of persons with an SCI injury sustained more than 20 years ago (Lidal et al., 2009). An interesting finding in these two studies was that the proportions of persons that had been employed at "some point" after injury were considerably higher than the employment rates taken at the time of these studies (65% versus 35% (Lidal et al., 2009), and 70% versus 45% (Solheim & Leiulfsrud, 2018)). These results suggest that some of the persons with SCI who successfully returned to the labour market were not able to remain in the labour market. The odds of obtaining work after injury were higher in persons of a younger age at injury, higher in males versus females, higher for persons with paraplegia versus tetraplegia, and for persons classified as AIS D-E compared to more severe SCI (Lidal et al., 2009).
Thus, to gain further knowledge regarding labour market participation in the SCI population, studies with information on both employment and sickness and disability benefits are needed to achieve a more complete picture. There is a need for longitudinal data and more comprehensive employment measures to do in-depth analysis of employment trajectories beyond employment levels (Bloom et al., 2019).

Furthermore, persons with SCI often experience restrictions or barriers to participation in different domains, including employment or social-recreational activities (Gupta et al., 2019). Participation can be an important determinant of QoL (1), and it is therefore reasonable to assume that increased participation for people living with SCI could improve their QoL.

1.3.2 Quality of life

QoL is a broad concept and has been defined by the 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 (The WHO qol Group, 1998).

QoL is an important factor in human life. It is therefore also important in health care settings and clinical research, and has been widely used as a clinical outcome. QoL has been operationalized in strongly diverging ways across studies (Post, 2014). In the health care field it is frequently measured as "Health-related" QoL (HRQoL) (Tate et al., 2002). In the last decades it has been more common to make a distinction between objective QoL (for example, housing or access to clean drinking water) and subjective QoL (the subjective experience of QoL) (Post & Noreau, 2005). Subjective QoL may be further subdivided into a cognitive component that comprises life satisfaction and an emotional component that includes affective states and mental health (Post & Noreau, 2005; van Leeuwen, Kraaijeveld, et al., 2012).

Many persons with SCI experience lower QoL, as shown by higher levels of distress, worse mental health, and lower life satisfaction levels among persons with SCI than in the general population (Carrard et al., 2020; Post & van Leeuwen, 2012). Studies have indicated that decreased mobility (Putzke et al., 2002; van Koppenhagen et al., 2008), suffering secondary complications (Lidal et al., 2008; Putzke et al., 2002; van Koppenhagen et al., 2008), pain (Muller et al., 2017; van Koppenhagen et al., 2008), and unemployment (Kent & Dorstyn, 2014; Lidal et al., 2009) are related to lower QoL. On the other hand, psychosocial characteristics such as higher self-efficacy (van Leeuwen, Post, et al., 2012), good social skills (van Leeuwen, Post, et al., 2012), more social support (Post & van Leeuwen, 2012), and a feeling of acceptance (Aaby et al., 2020) have been recognized to be related to increased QoL. The associations between QoL and age, sex, education, injury level, and injury duration are uncertain (Post & van Leeuwen, 2012; Putzke et al., 2002; Tate et al., 2002). However, request has been made for variation in study design, inclusion criteria, measurement instruments, and cohort studies with a representative sample and a sufficient sample size (Post & van Leeuwen, 2012).

In Norway only two previous studies reported QoL as the main outcome among persons with SCI. HRQoL (measured with the 36-Item Short Form Health Survey (SF-36)) in persons with long-standing SCI (more than 20 years duration) was decreased compared to norm data in a cross sectional study of traumatic SCI among 165 patients who had been admitted to Sunnaas Hospital (Norway) between 1961-1982 (Lidal et al., 2008). This study from Lidal et al. showed a lower HRQoL among individuals who reported health problems or symptoms compared to individuals reporting no health problems at all. Furthermore, being employed was related to better HRQoL (Lidal et al., 2008). A somewhat surprising finding for the authors in this study was the clear indication that HRQoL was better in the Norwegian SCI sample compared to what has been reported in other international studies (Lidal et al., 2008). The authors discussed three possible explanations as to why their study found higher SF-36 scores than shown by others: 1) generally high incomes and high standard of living in Norway, 2) the Norwegian welfare system, and 3) adaptive strategies developed over time that allow individuals with SCI to cope with complications and deterioration in function. Lidal et al. also used life satisfaction scores measured with the Life Satisfaction Questionnaire (LiSat-11) in their study on employment (Lidal et al., 2009). They found that 63% rated their life as a whole as satisfying or very satisfying (Lidal et al., 2009). Higher average life satisfaction was reported by the employed participants compared to those who were not employed (Lidal et al., 2009).

Other Norwegian studies have measured QoL in relation to other outcomes, e.g. bladder function (Hagen & Rekand, 2014) and body-weight supported locomotor training (Piira et al., 2020). Others have looked at specific aspects of QoL, such as patients' experiences of hope and suffering after SCI (Lohne & Severinsson, 2005), the immediate experiences following SCI (Lohne, 2009), resilience after SCI (Quale & Schanke, 2010), and posttraumatic stress symptoms after SCI (Quale et al., 2009).

1.3.3 Caregiving

Disability places a set of extra demands or challenges on the family and most of these demands last for a long time. Within the ICF framework, the WHO also recognizes the burdens placed on families as a result of a family member's poor health (World Health Organization, 2001). In what is defined as third-party disability, family members may also experience a decline in activity and participation because of their loved one's condition.

Many individuals with SCI depend on support from others (paid or unpaid) after rehabilitation (Smith et al., 2016). Like patients with SCI, the family members must adapt to the new situation. Many next of kin (close relatives, spouses, etc.) provide extensive support to individuals with SCI (Post et al., 2005). This support is often necessary for persons with SCI to maintain living at home and to retain their well-being (Bickenbach, 2013). Provided support varies from assistance with practical everyday support, such as dressing and transportation, to emotional support. Therefore, SCI often drastically disrupts the lives of both individuals with SCI and the people surrounding them.

Research shows that characteristics such as age, sex, level of education, occupation status, and type of relationship between caregiver and care recipient can influence the level of caregiver burden (Adhikari et al., 2020; Eline W. M. Scholten et al., 2018; Smith et al., 2016). Additionally, the personal and injury characteristics of the person with SCI receiving support may impact the provided support and the perceived caregiver burden (Smith et al., 2016). However, most next of kin studies are based on self-reported data on injury characteristics provided by the caregiver (Smith et al., 2016), and studies using clinical register data, which can be available from SCI quality registers, are needed.

The demands placed on the next of kin of persons with SCI can affect various life areas. It has been found that next of kin can experience strained relationships, less control over life, increased stress, and financial difficulties (Boschen et al., 2005; Lynch & Cahalan, 2017; Zarit et al., 1986). Only a few studies exist on the objective burden of support (Gemperli et al., 2020; Post et al., 2005; Eline W. M. Scholten et al., 2018), caregiver participation (Ellenbogen et al., 2006), and positive caregiver experiences (Charlifue et al., 2016). However, most studies in the field are restricted to measuring the impact of SCI on one or two life areas of next of kin; thus, the broader picture is lacking.

Caregiver studies have shown a clear association between care burden and QoL, revealing that the greater the burden, the worse the QoL (Nogueira et al., 2012). Next of kin of persons with SCI may also experience restrictions to participation due to their caregiver role. However, most informal caregiving studies focus on psychological outcomes, while areas like participation have been less studied (Ellenbogen et al., 2006; Rodakowski et al., 2012).

No studies about the next of kin of persons with SCI living in Norway existed when this thesis was initiated.

1.3.4 The International Spinal Cord Injury Community survey

The International Spinal Cord Injury Community survey (InSCI) was initiated during work on this thesis (Bickenbach et al., 2020). The InSCI study is a cross-sectional survey collecting self-reported data from the patient. InSCI aims to gain information about the lived experience of persons with SCI and the societal response within and across diverse nations - partially similar to the aim of this thesis. Norway was one of 22 countries participating, and a total number of 12.591 individuals with SCI around the world participated (Fekete et al., 2020). There have been published findings from the InSCI study in the area of experience of living with SCI (Pacheco Barzallo et al., 2020; Post et al., 2020; Reinhardt et al., 2020).

2 Aims of the thesis

As commented on in the introduction, several knowledge gaps still exist regarding living with SCI. Firstly, studies with a stronger design can provide a better foundation for understanding the influence of SCI on labour market participation. Secondly, more studies on participation and QoL following SCI, assessed with validated generic measurement instruments in a representative sample, may contribute to new knowledge. Thirdly, studies about the next of kin of persons with SCI are lacking in Norway.

2.1 Overall aim

The overall aim was to provide new knowledge about living with SCI, specifically on participation, quality of life, and caregiving among persons with a SCI and their next of kin (Figure 6).

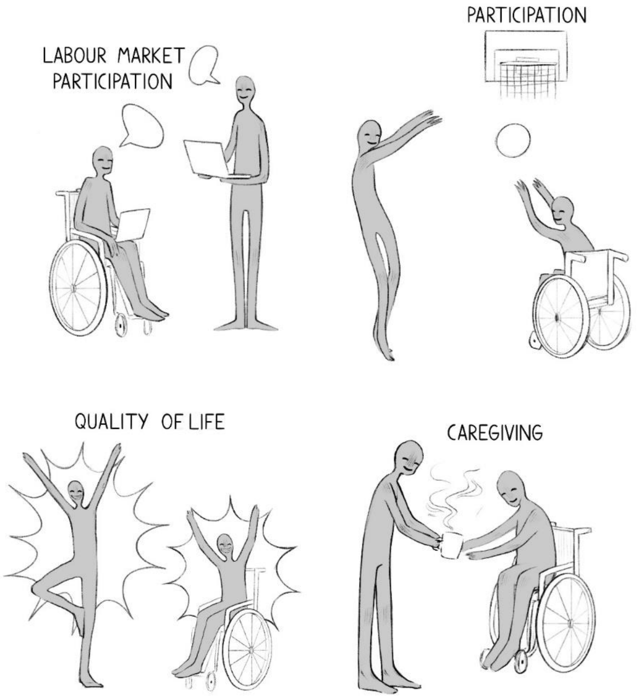


Figure 6. Main areas of focus in this thesis.

(Illustration by Juni Pape)

2.2 Specific aims

Three studies with the following specific aims were conducted to answer the overall aim of the thesis:

Study 1

1. To describe labour market participation post SCI for patients receiving pay for work the year before SCI.
2. To compare labour market participation following SCI with a control group from the general population.
3. To investigate the impact of patient and SCI characteristics on labour market participation after SCI.

Study 2

4. To describe the association between sociodemographic and SCI characteristics with participation and QoL (life satisfaction and mental health).
5. To detect groups of persons with SCI at risk for low participation or poor QoL.
6. To study the association between participation and QoL in persons with SCI.

Study 3

7. To describe next of kin of persons with SCI.
8. To investigate how personal characteristics of next of kin and the injury characteristics of the related person with SCI influence different life areas of next of kin: caregiving (objective and subjective burden of care, and positive experiences), participation, and QoL (life satisfaction and mental health).

3 Methods

Three studies were performed to achieve the aims of this thesis. The methods for each study are described in detail in their associated papers. This chapter provides an overview on the study design, setting, data sources, participants, data management, variables, ethical considerations, and analyses for these studies.

3.1 Design

Observational study designs (also referred to as nonexperimental epidemiologic studies) were chosen for this thesis due to its aim.

Study 1 was a cohort study following patients with SCI from the Norwegian SCI Registry (NorSCIR) and a matched control group taken from the general Norwegian population over a span of seven years using Norwegian population registry data on employment, education, income, and social security benefits.

In **Study 2**, persons registered in the NorSCIR between 2011 and 2017 (first rehabilitation setting, baseline) were invited to participate in a survey ("*Survey among persons with SCI*") performed in 2019 (community setting, follow-up).

Study 3 included survey data from next of kin ("*Next of kin survey*") performed in 2019-2020, which were linked to data on the related persons with SCI in the NorSCIR.

Figure 7 shows an overview of the three studies included in this thesis.

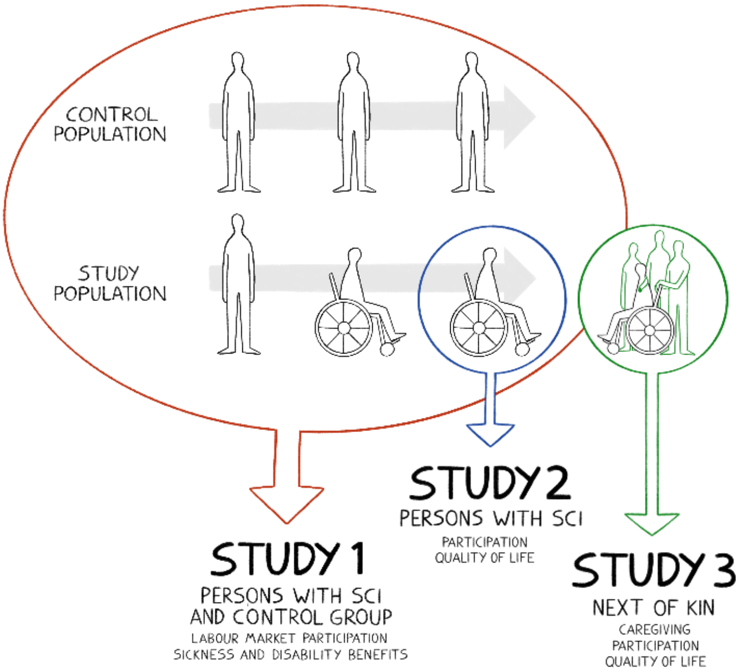


Figure 7. An overview of the three studies included in this thesis. The arrows in the circle for Study 1 indicate longitudinal study design 1, which starts one year before the spinal cord injury.

(Illustration by Juni Pape)

3.2 Setting

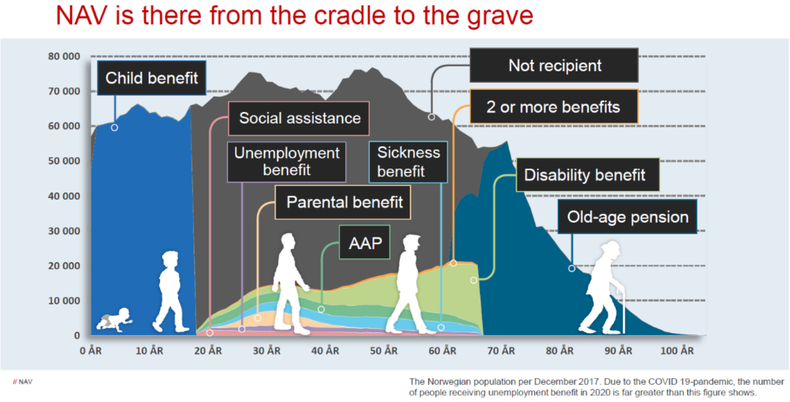
3.2.1 Norwegian health care system

Norway provides effective and high-quality medical care, and Norwegians enjoy long and healthy lives (World Health Organization, 2020). Norway has a public health system that includes all citizens with a permanent address in the country, providing health care for everyone independent of insurance status (World Health Organization, 2020).

The Norwegian health-care system can be characterized as semi-decentralized. Since 2002 the responsibility for specialist care has lain with the state, and municipalities are responsible for primary care and social services. Rehabilitation is provided at both primary (physiotherapy, occupational therapy, etc.) and secondary (specialized rehabilitation) levels. Secondary rehabilitation services are provided in hospitals in dedicated general rehabilitation departments or specialized units, such as specialized SCI rehabilitation units. Rehabilitation, especially postoperative rehabilitation, may also be provided in private rehabilitation institutions contracted by the regional health authorities; this is free of charge if a general practitioner or a hospital refers the patient. Norway also has a well-developed system of long-term care compared to other countries in Europe. Long-term care is provided in three types of settings: patients' homes, nursing homes, and sheltered housing run by the municipalities (World Health Organization, 2020).

3.2.2 Norwegian social security system

All persons who are either a resident or working as employees in Norway are insured under the National Insurance Scheme, managed by the Norwegian Labour and Welfare Administration (NAV) (Norwegian Labour and Welfare Administration, 2019a) (Figure 8). Employed people can be granted sick leave compensation covering up to 100 percent of income for a period of maximum 52 weeks if they are unable to work due to an illness or injury. After 52 weeks, Norwegian residents with a reduction in work ability of at least 50 percent due to illness or injury may apply for the long-term benefits - work assessment allowance (AAP) and disability pension (DP) - to compensate for loss of income. While AAP is a temporary benefit (max three years) requiring active treatment and/or rehabilitation measures, DP is granted on a permanent basis to those whose earning capacity is permanently reduced. Both AAP and DP cover approximately 66% of the income, and up to a maximum of six times the national insurance basic amount (G) for each year (1G=106 399 Norwegian kroners / approximately 11 033 euro (as of 21.3.2022).



The Norwegian population per December 2017. Due to the COVID 19-pandemic, the number of people receiving unemployment benefit in 2020 is far greater than this figure shows.

Figure 8. National Insurance Scheme (NAV) at a glance. (From annual report NAV 2020: "*NAV in numbers and figures*" (Norwegian Labour and Welfare Administration, 2021), with permission from NAV)

3.3 Data sources

The Nordic countries' have several national registries, including nationwide public registries and medical quality registries containing individual-level data, that allow for register-based cohort studies that are impossible in most other countries (Smith Jervelund & De Montgomery, 2020). These registries can be linked through a common key, the unique personal identification number assigned to all residents in the Nordic countries. Strengths of register-based epidemiology are e.g., already existing data, large sample sizes, and often complete data. The use of register data is therefore more and more recognized (Malmivaara, 2013; Thygesen & Ersboll, 2014).

This was utilised in the three studies in this thesis, where data was taken from the Norwegian SCI registry (NorSCIR), Statistics Norway (SSB), and Norwegian Labour and welfare administration (NAV). In addition two surveys were conducted.

Figure 9 shows a schematic presentation of the data sources used in this thesis. A description of the data sources is given here. The description of the variables included is given in the next section.

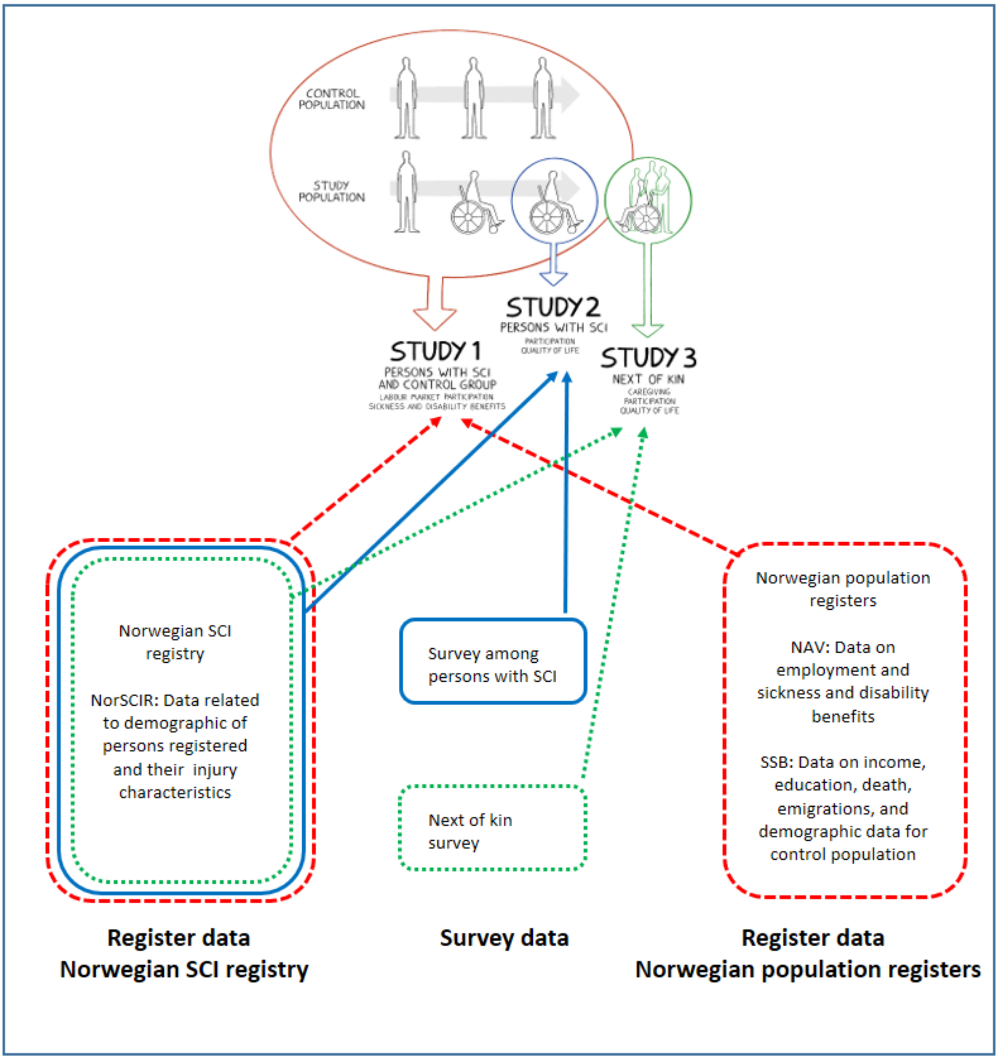


Figure 9. Schematic presentation of the data sources in this thesis.

(Study 1=red dashed line, Study 2=blue solid line, and Study 3=green dotted line

3.3.1 Norwegian Spinal Cord Injury Registry

The Norwegian Spinal Cord Injury Registry (NorSCIR) is a national medical quality registry for SCI care and in this thesis used as data source in each of the studies (NorSCIR, 2022). NorSCIR has been in operation since 2011 and was approved as a national medical quality registry by the Ministry of Health and Care Services in 2012. All SCI patients admitted for primary rehabilitation and later follow-up to one of the three specialized SCI units are included. Registration in the registry is voluntary, and written informed consent is obtained before registration occurs.

NorSCIR is based on International SCI Data Sets (Biering-Sorensen et al., 2006). The registration is electronic and runs on the Medical Registry System (MRS) developed by the Central Norway Regional Health Authority IT department (Hemit IT). Data are transferred via the Norwegian Health Network (NHN). High data quality is considered to be one of the most essential elements of the registry. NorSCIR ensures high data quality through regular data assessments (Halvorsen & Pettersen, 2022). The purpose of NorSCIR is to improve quality of care, establish and monitor clinical guidelines, and serve as a resource for research by providing comprehensive data on SCI care (www.norscir.no).

3.3.2 Norwegian population registers

The population registers from the Norwegian Labour and Welfare Administration (NAV) (Norwegian Labour and Welfare Administration, 2019a) and Statistics Norway (SSB) (Statistics Norway, 2022a) were used as data sources in Study 1.

The Norwegian Labour and Welfare Administration (NAV) provided information on dates of sickness absence benefit, work assessment allowance, disability pension, and old age pension (Norwegian Labour and Welfare Administration, 2020). The State Register of Employers and Employees (Aa Register) is owned and managed by NAV and provided information on employment status (Norwegian Labour and Welfare Administration, 2019b). The Aa Register is a basic data register of employment in Norway and lists all employment relationships, with a few exceptions. The register was established in 1978 when the sick pay scheme was introduced. The Norwegian Labour and Welfare Administration and others who need information on employment to accomplish public tasks, including research, can use the register.

Statistics Norway (SSB) is the national statistical institute of Norway and the main producer of official statistics. SSB is responsible for collecting, producing, and communicating statistics related to the economy, population, and society at national, regional, and local levels. SSB can provide access to microdata for research purposes (Statistics Norway, 2022b).

3.3.3 Survey data

Survey data was used in Studies 2 and 3.

Two surveys were performed: one among persons with SCI (Study 2) and one among next of kin of persons with SCI (Study 3). The surveys were developed largely by using validated generic measurement instruments (outcome measures are presented below). The user representatives were involved in the development of the surveys and to ensure that relevant questions were included.

In case the measure instruments were not available in Norwegian, translations from English to Norwegian were performed according the guidelines from the World Health Organization for the process of translation and adaptation of instruments (World Health Organization, 2009).

The electronic form-based data collection system eFORSK (Klinforsk, 2021) was used for data collection in Studies 2 and 3. eFORSK is developed and owned by the Central Norway Regional Health Authority IT department (Hemit IT) and ensures secure digital communication with patients via “HelseNorge.no”, “Digipost”, and paper forms in the mail. A digital invitation was sent to all eligible persons. Those not answering the digital questionnaire were invited by postal mail. 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” to create awareness among those who were invited. Up to two reminders were sent out to non-responders.

3.4 Participants

Figure 10 shows a flowchart of the participants of the three studies.

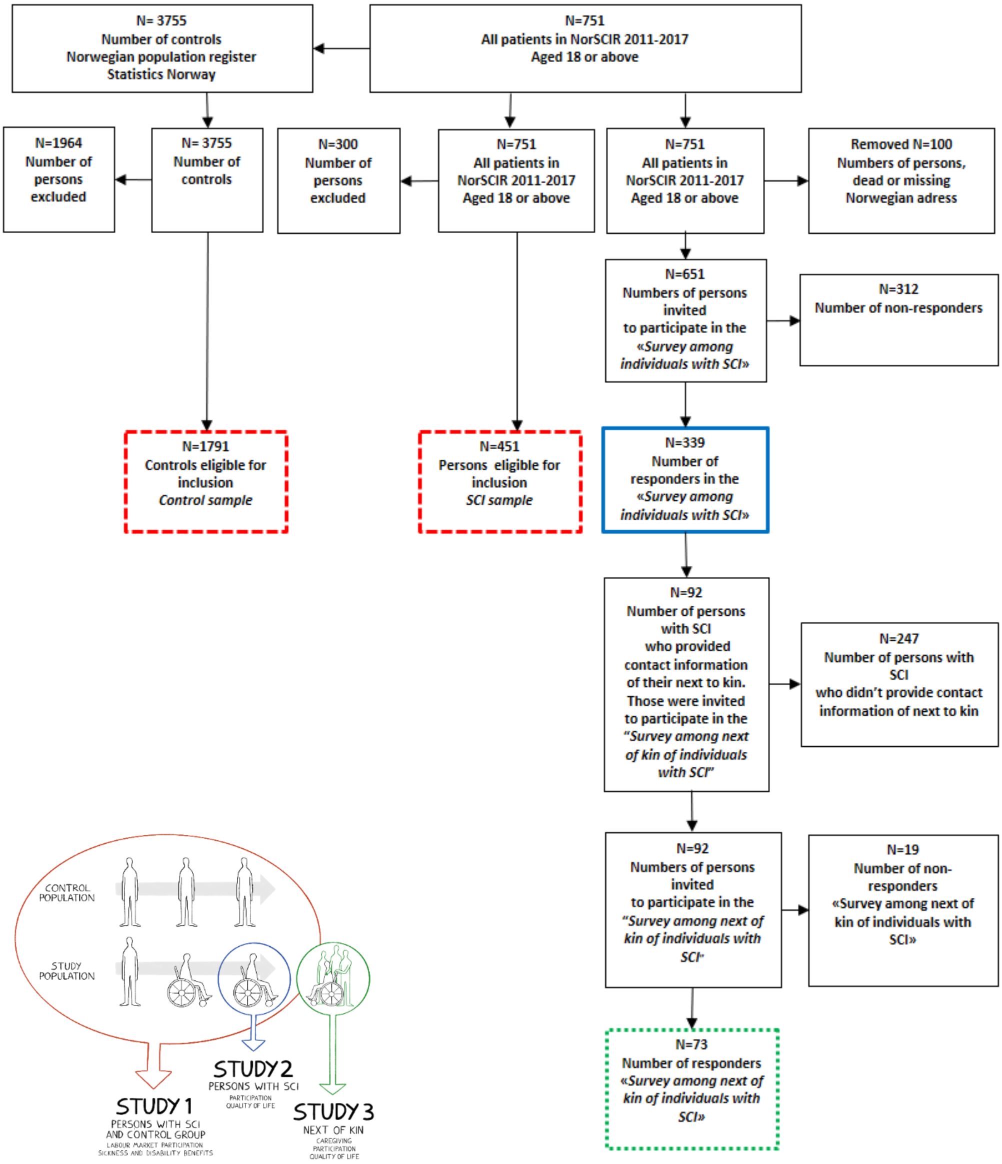


Figure 10 Flowchart of the participants of the studies, indicated by coloured boxes.

(Study 1=red dashed line, Study 2=blue solid line, and Study 3=green dotted line)

3.4.1 Inclusion criteria Study 1

There were two samples in Study 1: the SCI and the control.

The SCI sample.

The inclusion criteria for the SCI sample were all patients who experienced traumatic or non-traumatic SCI, admitted to one of the three SCI units in Norway, registered in NorSCIR from 01.01.2011 to 31.12.2017, of working age (16 to 66 years at time of injury), living in Norway in the month before the injury, and who had an annual employment income >0 NOK in the year before SCI. We used 66 years of age as the upper limit because the legal retirement age in Norway is 67 years. The lower limit of 16 years was chosen as this is the last year of compulsory education.

The control sample.

A control sample was randomly drawn from the general population by Statistics Norway (SSB), matching the patients in NorSCIR (SCI sample) for year of birth, sex, county of residence, and level of education. Five controls were drawn for each patient. Controls were assigned the same "date of injury" as their respective patients. Only controls living in Norway and employed, according to the same definition as the SCI sample, were included in the analyses.

3.4.2 Inclusion criteria Study 2

The inclusion criteria for this study were persons aged 16 years or older (thus 18 and above at the time of the survey (follow-up)), registered for the first time in the NorSCIR between 01.01.2011 and 31.12.2017, and registered to be alive and living in Norway based on the linkage to the National register at the time of the survey (follow-up).

3.4.3 Inclusion criteria Study 3

The inclusion criteria was being designated by the person with SCI participating in the "Survey among persons with SCI" as the closest next of kin, defined in the questionnaire as "A person who provides unpaid support, or the one who is closest to you. Usually it is a partner or other close relative such as parent, child, or sibling".

3.5 Data management

An important aspect of managing data is protecting the privacy of individuals who participate in research projects. The European General Data Protection Regulation (GDPR) regulates the protection of natural persons in the processing of personal data (European Commission, 2016). A Data Protection Impact Assessment (DPIA) was completed in advance of the data collection for the three studies.

SSB created the key links for the linkages of the NorSCIR, NAV, and SSB data files. The researchers had no access to the key links. Data files were transferred encrypted between NorSCIR, NAV, SSB, and in the end to the researcher (without key link). Datafiles were stored at a secure area, dedicated to this research project, at the server of St Olav's Hospital.

3.6 Variables

Table 1 gives an overview of the study variables included in the regression analyses in the three studies, before a more detailed description of the main variables is given.

Table 1. Overview study variables included in the regression analyses in the three studies

Study 1	**Study 2**	**Study 3**
Age group at injury	*Age-groups at follow-up*	*Age-groups*
16-29 years	18 to 29 years	< 55 years
30-39 years	30-59 years	55-67 years
40-49 years	60+ years	> 67 years
50-59 years	*Sex*	*Sex*
60-66 years	Male	Male
Sex	Female	Female
Female	*Level of education*	*Level of education*
Male	Primary	Primary
Level of education	Secondary	Middle
Primary	Higher	Higher
Secondary	*Family income per year*	*Vocational status*
Higher	Below 250.000 NOK	Currently working or student
*Work income **	250.000 to 500000 NOK	Retirement pension
0-299.999 NOK	500.000 to 750.000 NOK	Social welfare recipient
300.000-499.999 NOK	750.000 to 1 million NOK	*Own income per year*
500.000-999.999 NOK	Above 1 million NOK	Below 500.000
1.000.000 NOK or above	*Main daily activity*	500.000 and above
*Sickness/disability benefit***	Currently working	*Relation to patient*
No benefit	Retirement age	Partner
Benefit	Social welfare recipient	Family or other
*Having an employer ***	Students	
No	Other (homemaker, jobseeker)	
Yes	*Living situation*	
	Alone	
	Together	
SCI impairment group (level and AIS)	*SCI impairment group (level and AIS)*	*SCI impairment group (level and AIS)*
Tetraplegia AIS A-C	Tetraplegia AIS A-C	Tetraplegia AIS A-C
Tetraplegia AIS D	Tetraplegia AIS D-E	Tetraplegia AIS D
Paraplegia AIS A-C	Paraplegia AIS A-C	Paraplegia AIS A-C
Paraplegia AIS D-E	Paraplegia AIS D-E	Paraplegia AIS D
Cause of SCI injury	*Cause of SCI injury*	
Traumatic SCI	Traumatic SCI	
Non-traumatic SCI	Non-traumatic SCI	
Year of injury	*Time since discharge*	*Time since discharge*
Injury 2011-2014	4 years or less	4 years or less
Injury 2015-2017	More than 4 years	More than 4 years

* During year before injury
** 75% of monthly registrations during the one-year interval before SCI
Abbreviation: NOK, Norwegian kroner. SCI, spinal cord injury. AIS, American Spinal Injury Association Impairment Scale.

3.6.1 Labour market participation (Main outcome Study 1)

Labour market participation was measured by two outcomes:

1) Receiving any amount of pay for work (>0 NOK/EUR)

Any income from work and self-employment. Annual observations (0/1) were used. Assessment time points were one-year intervals from date of injury to six years (72 months) after injury.

2) Receiving sickness and disability benefits

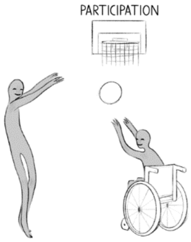
The outcome variable included sickness absence benefit, work assessment allowance, and/or disability pension, and was dichotomized as receiving any of the three benefits (1) or not receiving any benefit (0). The monthly observations were used as the basis for outcome assessment in one-year intervals. To be registered with outcome, the persons had to be registered with the outcome in at least 9 out of 12 months (or at least 75% of monthly registrations during the one-year interval). Assessment time points were one-year intervals from one year (12 months) before injury to six years (72 months) after injury.

Additional outcomes included:

1) Mean employment income as a continuous variable.

2) Each of the sickness/disability benefits separately.

3.6.2 Participation (Main outcome Studies 2 and 3)



Participation was measured with The Utrecht Scale for Evaluation of Rehabilitation-Participation instrument (USER-Participation) (Post et al., 2012).
USER-Participation was developed based on the ICF to assess objective and subjective participation. The psychometric properties of the USER-Participation were studied (Mader et al., 2016) and translated from Dutch to Norwegian for this study.

The USER-Participation consists of 32 items and assesses three aspects of participation: frequency, experienced restrictions, and satisfaction. The USER-Participation can also be used in people without physical disabilities, such as patients with coronary heart disease (Mol et al., 2021), or people without health problems, such as next of kin (Cox et al., 2020). The three scales can be used separately, and researchers have used diverging combinations depending on their research questions and other measures in the database (Tielemans et al., 2015).

In Study 2, all scales (frequency, experienced restrictions, and satisfaction) were administered, but the satisfaction measure was not included because of the considerable conceptual overlap between the satisfaction items of the USER-Participation and the WHOQoL-5 items (described below).

In Study 3 only the frequency and satisfaction scales were administered because we did not expect relevant degrees of physical limitations in the next of kin. The satisfaction scale was, for the same reason as in Study 2, not included in the analyses.

The frequency scale measures objective participation and consists of four items on vocational activities and seven items on leisure and social activities. The four 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 hours per week or more). The seven items on leisure and social activities address the frequency in the last four 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).

3.6.3 Quality of life (Main outcome Studies 2 and 3)

QoL was measured using two components: life satisfaction and mental health.

1) Life satisfaction

Life satisfaction was measured with a selection of five items from the World Health Organization QoL-BREF assessment covering satisfaction with overall QoL, health, daily activities, relationships, and living conditions (WHOQoL-5) (Geyh et al., 2010). 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 WHOQOoL-5 is available in Norwegian and has previously showed good internal consistency reliability and cross-cultural validity in persons with SCI (Geyh et al., 2010).

2) Mental health

Mental health was measured with the MHI-5 that refers to the Mental Health subscale of the Medical Outcomes Study Short Form Health Survey (SF-36, available in Norwegian). MHI-5 consists of five 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 (van Leeuwen, van der Woude, et al., 2012). Respondents rated the frequency of each item during the previous four 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).

3.6.4 Caregiving (Main outcome Study 3)

Caregiving was measured by four outcomes, two of them concerning subjective burden of care because it has been recommended to use two instruments that complement each other (van Exel, Brouwer, et al., 2004): one on the different dimensions of burden, and one on the caregiver's overall assessment of burden.

1) Objective burden of care
The objective burden for next of kin was assessed by a measure of "types and frequency of support" (Post et al., 2005; Eline W. M. Scholten et al., 2018). The author of the instrument did not give a name to this instrument when it was introduced. The measure includes three categories of support: activities of daily living support (thirteen items), other practical support (nine items), and emotional support (two items). Response categories are never (1), sometimes (2), often (3) and always (4). The total score is the mean of the item scores (range 1-4). The instrument was translated from Dutch to Norwegian for this study.

2) The caregiver strain index (CSI) (Robinson, 1983) evaluates strain related to care provision by asking the responder to think of the person he/she is caring for and to indicate if the following 13 dimensions apply to him/her (yes, no, not applicable), such as sleep disturbances, inconveniences, physical strain, and emotional adjustment. The total CSI score is calculated by summing up the "yes" responses, ranging from 0 to 13. Positive responses to seven or more items on the index indicate a greater level of strain (Robinson, 1983; Eline W. M. Scholten et al., 2018). The CSI has been validated (Post et al., 2007; Robinson, 1983) and the available Norwegian version was used (Lohne et al., 2012).

3) The self-rated burden (SRB) (van Exel, Scholte op Reimer, et al., 2004) is a single question: "How demanding is it for you to provide care at the moment?" It is scored on an 10-point scale, from 0 "not demanding at all" to 10 "much too demanding". SRB is feasible and

considered to be at least as valid as other measures of burden (van Exel, Scholte op Reimer, et al., 2004). It was translated to Norwegian for this study.

4) Positive caregiver experiences

The five positive items that were added to the CSI in the Caregiver Strain Index Expanded (Al-Janabi et al., 2010) were used to describe the positive experiences of caregiving. Positive experiences related to care provision are assessed by asking the responder to think of the person he/she is giving care to and to indicate if the following five dimensions apply to him/her (yes, no, not applicable), such as: I am happy to care and I handle the care fine. It was translated from English to Norwegian for this study.

3.7 Ethical considerations

Ethical approval for this project was obtained from the Regional Committee for Medical and Health Research Ethics in Mid Norway (2018/294/REK midt). The project is registered in clinicaltrials.gov, No: NCT03709732.

Registration in the NorSCIR is voluntary with a written informed consent before registration occurs. Persons giving consent to participate in NorSCIR accept that their information can be used for research purposes, including linkage with a range of national registers.

All applicable institutional and governmental regulations concerning the ethical use of human volunteers were followed during the course of this research.

3.8 Analyses

Stata® version 16.0 (StataCorp, College Station, Texas, USA) was used for all statistical analyses.

3.8.1 Analyses Study 1

Descriptive statistics were used to present characteristics of the study samples. These included the number and percentage of participants in the SCI sample and control sample who received (+) or did not receive (-) pay for work and/or sickness and disability benefits each year of follow-up, and the distribution of participants in the SCI sample and control sample in employment income groups, each year of follow-up.

The longitudinal data in Study 1 consists of several observations for each study participant, measured at different occasions/time points. Consequently, the data needed to be treated as two level data, with observations (level 1) nested within the participants (level 2) (Rabe-Hesketh & Skrondal, 2012).

We explored the association between time during follow-up and labour market participation using general estimation equations' (GEE) logistic regression analyses. Analyses included time as year in relation to injury (each year as a category, from year before to six years after) and repeated measures of the two dichotomous labour market participation outcomes (pay for work and sickness/disability benefits, assessed each year of follow-up for each participant). We performed separate analyses for the SCI and control samples, with adjustment for age, sex, and educational level. Estimates from the analyses were used to calculate and graphically present the level (percentage) of labour market participation at each one-year interval during follow-up.

For the SCI sample we used a similar approach to assess labour market participation over time for subgroups of age, sex, level of education, SCI impairment, and cause of injury. A separate GEE analysis was performed for each grouping variable by including it in the GEE model and adding an interaction term with the time variable. All analyses were adjusted for age, sex, and level of education.

For patients with SCI we further explored the impact of various personal and SCI characteristics on labour market participation after injury using three different models (GEE logistic regression, with six repeated outcome assessments; from injury to six years after). Model A included adjustment for time, age group, sex, and level of education; Model B included additional adjustment for injury variables (SCI impairment group, cause of injury, year of injury); and Model C further added adjustment for pre-injury employment (employment income, employment status, and medical benefits before injury).

We compared labour market participation between SCI patients and controls within matched groups using fixed effect logistic regression models. This analysis compares patients only with their designated controls, automatically adjusting for year of birth, sex, county of residence, and level of education (matching variables), and also accounting for the unequal number of controls per patient in the total samples. Estimates from the analyses were used to calculate the absolute and relative difference (prevalence difference in %-points and odds ratio with 95%CI) between the SCI and control sample for labour market participation at one year before injury, one-to-three years after injury, and four-to-six years after injury.

Supplementary analyses included alternative outcome measures for labour market participation (assessed each year of follow-up for each participant); 1) mean employment income as a continuous variable (SCI and control samples) and 2) each of the sickness/disability benefits separately; sickness absence benefit, AAP, and DP (SCI sample only). The association between time (year in relation to injury) and each outcome was analysed using GEE linear or logistic regression, with adjustment for age, sex, and education.

3.8.2 Analyses Study 2

Descriptive statistics were used to present characteristics of the participants and non-participants, and proportions of participants answering each of the answering categories on the single items in the survey. Comparisons of baseline characteristics between participants and non-participants were done using t-tests for continuous and chi-square for categorical variables.

In separate analyses for each dimension of participation (frequencies and restrictions), and QoL (life satisfaction and mental health) as dependent variables, the associations with injury and sociodemographic characteristics as independent variables were assessed by bivariable analyses (one-way analysis of variance (ANOVA)) and multivariable linear regression analyses. 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.

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

3.8.3 Analyses Study 3

Descriptive statistics were used to present characteristics of the next of kin of persons with SCI, and proportions of participants answering each of the answering categories on the single items in the survey. Furthermore, descriptive statistics were also used to present characteristics of persons with SCI related to next of kin responders ("Participating") and those who were asked to provide contact information on next of kin ("Not participating"). Comparisons of baseline characteristics between participants and non-participants were done using t-tests for continuous variables, chi-square for categorical variables, and with Fisher's exact test for impairment groups. In separate analyses with objective burden, participation, and each dimension of subjective burden (CSI and SRB) and QoL (life satisfaction and mental health) as dependent variables, the associations with characteristics of next of kin and the injury characteristic of their related person with SCI as independent variables was assessed by multivariable linear regression analyses adjusted for sex and age as a continuous variable.

4 Results

In this chapter, a summary of the main results from the three studies is presented. More detailed results are presented in the respective papers. Table 2 shows an overview of all participants in the three studies.

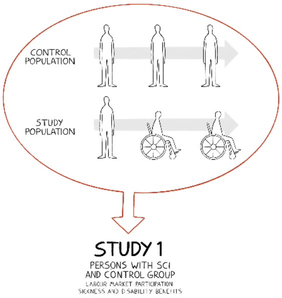
Table 2. Descriptive characteristics of the participants in the three studies.

	Study 1		Study 2	Study 3
	Patients N = 451	Controls N = 1791	N = 339	N = 73
Mean age at injury, years (sd)	44 (15)	43 (14)	53 (16)	
Mean age, years (sd)				56 (15)
Sex N (%)				
Male	343 (76)	1374 (77)	243 (72)	20 (27)
Female	108 (24)	417 (23)	96 (28)	53 (73)
Level of education N (%)				
Primary	117 (26)	395 (22)	50 (15)	8 (11)
Secondary/Middle	210 (47)	893 (50)	151 (45)	25 (34)
Higher	124 (27)	503 (28)	132 (40)	40 (55)
Cause of SCI N (%)				
Traumatic	301 (67)		203 (60)	
Non-traumatic	150 (33)		136 (40)	
Impairment groups (Level and AIS) N (%)				
Paraplegia, AIS D-E	159 (35)		123 (36)	
Tetraplegia, AIS D-E	113 (25)		102 (30)	
Paraplegia, AIS A-C	109 (24)		76 (22)	
Tetraplegia, AIS A-C	58 (13)		34 (10)	
Unknown or not applicable	12 (3)		4 (1)	

Abbreviation: SCI, spinal cord injury. AIS, American Spinal Injury Association Impairment Scale.

4.1 Study 1 (Paper I)

Labour market participation after spinal cord injury. A register based cohort study.



A cohort study was conducted including 451 persons with SCI identified from the Norwegian SCI Registry (NorSCIR) who had income from work in the year before the injury, and a matched control group of 1791 persons taken from the general Norwegian population. Longitudinal data on the period between one year before injury and up to six years after injury were analysed. Main measures of labour market participation were: 1) receiving any amount of pay for work, and 2) receiving sickness and disability benefits.

Results of the specific aims:

- Labour market participation post SCI for patients receiving pay for work the year before SCI:

The estimated percentage receiving pay for work among persons with SCI gradually decreased from 100% before injury to 63% (95% CI 57-69) six years after injury. The estimated percentage receiving sickness and disability benefits among persons with SCI was 18% before injury (95% CI 14-21), peaked to 87% during the first year after injury, and then decreased to 67% (95% CI 61-72) six years after injury. There was a gradual shift from short-term to long-term benefits during follow-up, with over half of SCI patients on disability pension (DP) at end of follow-up.

- Labour market participation following SCI compared with a control group from the general population:

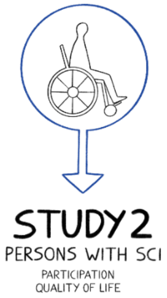
The estimated percentage receiving pay for work among the controls declined from 100% to 91% (95% CI 90-93) six years after injury. Among controls the estimated percentage receiving sickness and disability benefits rose from 8% before "injury" to 13% (95% CI 12-15) six years later. Comparison between the patients with SCI and their controls (within matched groups) showed that patients had 28%-point lower annual percentage of receiving pay for work 4-6 years after SCI, and a corresponding 36%-point higher annual percentage of receiving sickness and disability benefits.

- The impact of patient and SCI characteristics on labour market participation:

Patients with SCI with less severe neurological outcomes, higher level of education, younger age at injury, and a stronger pre-injury attachment to employment were more likely to have higher labour market participation.

4.2 Study 2 (Paper II)

Participation and quality of life in persons living with spinal cord injury in Norway.



In this study, persons registered in the NorSCIR between 2011 and 2017 were invited to participate in a survey performed in 2019. Of the 651 individuals invited to complete the follow up survey, 339 participated.

The frequency and restrictions scales of the Utrecht Scale for Evaluation of Rehabilitation-Participation were used to measure participation. QoL was measured as life satisfaction with the World Health Organization Quality of life assessment (WHOQoL-5), and mental health was measured by using the Mental Health subscale (MHI-5).

Results of the specific aims:

- The association between sociodemographic and SCI characteristics with participation and QoL:

Overall, sociodemographic characteristics were more prominently associated with QoL and participation than SCI characteristics. In particular, participants who reported to be currently working as their main activity and having a high family income had higher scores on all the four measures of participation and QoL than those not working and having lower income.

For both participation indicators (frequency and restrictions), significant and graded associations with age and education were apparent (younger age and higher level of education reported higher participation scores, indicating better participation). Participants living together with someone in general reported higher QoL, both regarding life satisfaction and mental health. The older age group reported higher mental health, while the youngest age group reported higher life satisfaction. Except for severity of injury and restrictions in participation, there were no strong associations between injury characteristics and self–reported participation frequencies, life satisfaction, and mental health one to eight years after injury.

- Groups of persons with SCI at risk for low participation and or poor QoL:

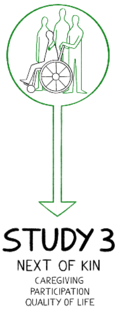
Persons with SCI who were not working or studying and had lower income more often reported lower scores for participation and QoL.

- The association between participation and QoL in persons with SCI:

Participation was strongly associated with life satisfaction and mental health.

4.3 Study 3 (Paper III)

The life situation of closest next of kin of persons living with spinal cord injury in Norway.



This study included a survey performed among 73 next of kin for persons with SCI. Survey data were linked to data on the related persons with SCI in the Norwegian SCI Registry.

Measures included types and frequency of provided support, Caregiver Strain Index (CSI), positive experiences, Self-rated Burden (SRB), frequency scale of the Utrecht Scale for Evaluation of Rehabilitation-Participation, life satisfaction (WHOQoL-5), and mental health (MHI-5).

Results of the specific aims:

- Description of the next of kin of persons with SCI in Norway:

The participants (73% partners, 73% female, mean age 56.4 years) gave various support to the person with SCI; they found it important to care and were happy to do so. Three out of four reported good mental health and life satisfaction, while one-fourth reported high levels of caregiver strain, especially related to emotional adjustments.

- Influences of next of kin personal characteristics and the injury characteristics of the related person with SCI, on different life areas of next of kin:

Higher levels of caregiver strain were reported by participants of working age (<67 years) and by those with middle level education. Female next of kin tended to express higher levels of overall burden than males. The only SCI injury characteristic associated with a life area of next of kin was impairment group tetraplegia AIS A-C (most severe disability); this next of kin group reported a higher objective burden of care.

5 Methodological discussion

Discussions of the strength and limitations in each study are provided in their associated papers. In this chapter there is a broader and, on some topics, more detailed discussion. The first section discusses reflexivity, because this is an issue that involves all phases of research. Thereafter follows a critical evaluation of the design, precision, and validity of the included studies, as well as remarks on issues that should be kept in mind when interpreting the findings.

5.1 Reflexivity

Reflexivity is examining one's own assumptions, beliefs, and judgments and critically considering how these influence the research process (Jamieson et al., 2022). Although reflexivity has traditionally been reported in qualitative research, it is relevant for research in general. I will reflect on what motivated me to initiate this project and how I might have influenced the different research phases.

My motivation mainly originated from my work as a Physical Medicine and Rehabilitation physician at the SCI specialized rehabilitation department of St Olav’s University Hospital in Trondheim. My experience has been that many patients and family members could be helped to be better prepared for this "new" life, as some struggled to participate in society after coming home from the hospital. I found the literature to be sparse on this topic in Norway.

Additionally, I was motivated by my work as the leader of the Norwegian and Nordic Medical Quality Register for SCI (NordicSCIR, 2022; NorSCIR, 2022). I knew about the opportunity for utilizing data from the NorSCIR and link it to other relevant data sources. I also saw it as a limitation, and still do, that we have limited patient reported outcomes and no information about next of kin in the register. Thus, I was motivated to make a connection between the clinical and administrative data in the register with the patients and next of kin experiences.

It is important to get input from others in order to reflect on one's own role and action. As a clinician working within Physical Medicine and Rehabilitation, I am a member of a multidisciplinary team working towards a common goal. This experience made me realize the need to establish a multidisciplinary research team to plan and realize this project. It was important for me get input from others and gain a broad perspective throughout all phases in this research project.

My main preconception before starting this project was similar to my motivation: that many patients struggled to participate in society, resulting in reduced QoL. Furthermore, I expected to find that the burden of care experienced by next of kin was quite high. However, during this project I realized that my preconception was, to a large extent, influenced by the individuals with SCI and their next of kin who I saw the most. These were typical persons and families who struggled and who needed extra support from our SCI specialized rehabilitation department. Thus, I unconsciously had a biased view of the status of persons with SCI and their next of kin in general.

The established research team for this research project included four supervisors and three user representatives. The four supervisors had valuable scientific expertise in different fields, from SCI via user involvement to register-based research. The involvement of user representatives in this work was motivated by the wish to make this research person-centred. The user representatives used their personal experience to provide input to all steps, from the study design to reporting the results.

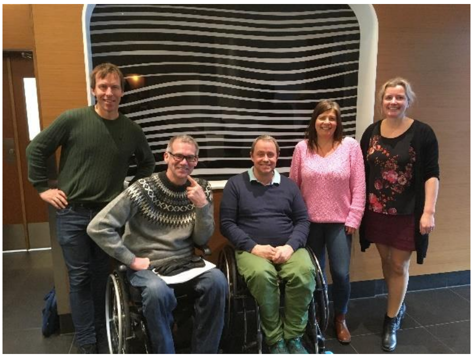


Image 1. First meeting with attendance of the three user representatives, main supervisor, and PhD candidate. From left to right: Aslak Steinsbekk, Steinar Mikalsen, Anders Nupen Hansen, Monica Engelsjord, and Annette van der Meer Halvorsen.
(*Image with permission from all participants*).

All members of this "multidisciplinary research team" have been involved in the research conception, design, and formation of the research questions. I think this ensured a broad perspective on all aspects of this research project, at least much broader than I would have managed on my own. And the dialogues helped me become aware of my own preconceptions. This was especially helpful in the discussion of the findings, where the regular meetings and the reflexive process we went through helped me avoid allowing my preconceptions influence the interpretation of the data analysis.

I put much effort into explaining the analyses and results in an understandable way to the involved user representatives, which enabled them to contribute to the discussions. We have had many fruitful discussions regarding the analyses, interpretation, and presentation of the results during the entire project. I learned a lot during those discussions, and I think it strengthened the quality of the research project and the papers. Furthermore, data analyses and results were presented and discussed in other research groups, “Patient Education and Participation” and the “Work and Health” research group. This also helped increase the understanding of the data and strengthened the results' consistency and credibility.

5.2 Study designs

The main objective of this thesis was to provide a descriptive overview of living with SCI. Observational study designs (also referred to as nonexperimental epidemiologic studies) were therefore used (Rothman et al., 2008). Observational studies are not designed to give definite answers regarding causal effects, but can describe the associations between the study variables and the outcomes (Rothman et al., 2008).

There was a longitudinal element in all studies, most prominent in Study 1 with the long follow up and less so in Studies 2 and 3. All studies used data from the initial hospital stay, primarily injury characteristics. This allowed for investigation of the prospective association between injury characteristics and the measured outcome up to 8 years later. Although such investigations cannot give definite answers on whether e.g., the injury characteristic is the cause of the self-reported participation, QoL, or caregiving among persons with SCI (Study 2) or next of kin (Study 3), it gives a better indication than a cross sectional study would. Thus, a strength of the studies in this thesis is their longitudinal design.

In Study 1 there was an additional element: a control group. Having a design with a control group, together with longitudinal data collection (following labour market participation over time based on register data) is an additional strength, and is a design not often used in SCI research (Lidal et al., 2007). Still, this design does not allow for claims about causal effect.

Thus, when utilising the findings from this thesis it must be kept in mind that the results are foremost a description of the current situation in Norway, and that the design only allows for conclusions about associations and not causal effects.

5.3 Precision (lack of random error)

All estimations in epidemiologic studies are done with a component of chance called random error (Rothman et al., 2008). Random error is a chance difference between the observed and true values of something. An estimate with little random error may be described as precise. Precision in observational studies depends on both the sample size and the efficiency of the study and may be evaluated using confidence intervals of the estimates. A confidence interval (CI) of 95% is most commonly used. Assuming absence of biases, the 95% CI will contain the true population value 95% of the time if the study is repeated an infinite number of times. A wide confidence interval indicates high variability (low precision), while a narrow confidence interval indicates low variability (high precision). In general, a larger study and one with more balanced groups (i.e., traumatic versus non-traumatic SCI) will produce estimates that are more precise than smaller sample and group sizes.

In this thesis, Study 1 comprised samples that were quite large (SCI sample N= 451, control sample N=1791) and included several observations per person. This resulted in narrow CI/high precision, especially in analyses assessing and comparing outcomes in and between the entire patient and control samples. Analyses regarding the smaller subgroups, such as SCI impairment groups (Level and AIS) and age groups, yielded less precise estimates with wider confidence intervals. Studies 2 and 3 in this thesis included smaller study samples (Study 2 N=339, and Study 3 N=73), and results like these generally have lower precision. This is particularly relevant when assessing the results from subgroup analysis within Study 2 and in Study 3.

5.4 Validity (lack of systematic error)

Validity refers to whether the findings from a study are valid or can be trusted. The validity of a study is usually separated into two components: internal validity and external validity. There are numerous possibilities to introduce systematic errors that can threaten the validity of the study when doing research. The presence of systematic errors may lead to incorrect results from the study itself (internal validity) or results that cannot be generalised to the intended population (external validity).

Internal validity refers to the strength of the conclusions drawn from the study. Assessing the internal validity is often done in terms of assessment of biases (Rothman et al., 2008). Bias can be defined as any systematic error in the design, conduct, or analysis of a study. Bias commonly arises from three different sources: 1) the approach adopted for selecting subjects for a study (selection bias), 2) the approach adopted for collecting or measuring data from a study (information bias), or 3) confusion of effects due to the effect of the exposure is mixed with the effect of another variable (confounding).

External validity (also called generalizability) refers to the ability to apply the outcomes of a study to other populations, settings, or patients (Rothman et al., 2008). Internal validity is essential to achieve high external validity, and biases and confounding must be kept to a minimum to achieve both internal and external validity.

5.4.1 Selection bias

Selection biases are distortions that result from the procedures used to select subjects for the study and from factors that influence study participation (Rothman et al., 2008).

Since all studies had NorSCIR as the starting point, the first question is whether or not the register is representative of all persons with SCI in Norway. The NorSCIR includes all patients (traumatic and non-traumatic) admitted for primary rehabilitation to one of the three specialized SCI departments. Registration in the registry is voluntary, and written informed consent is obtained before registration occurs. Annual analyses performed by NorSCIR reveal that >90% of all patients with SCI have consented to be registered in NorSCIR during the entire study period (Halvorsen & Pettersen, 2022). In addition, a potentially very small group of patients can be admitted to other departments or discharged directly home and therefore not captured in the registry; typically, those with very limited sequelae. Still, the study population from NorSCIR represents a major part of the Norwegian SCI population and using NorSCIR as a starting point for the studies probably does not introduce serious selection bias.

The control population in Study 1 was drawn from the entire Norwegian population by Statistics Norway (SSB), randomly selecting individuals matching the NorSCIR population on defined characteristics. Since the information collected on the controls from national registry data (NAV and SSB registers) has high completeness for all citizens living in Norway, and five controls were selected for each patient, the risk of introducing systematic errors related to selection in the control group was considered low.

The use of registry data from SSB and NAV in Study 1 ensured that no patients or controls were lost to follow-up, with complete registrations of the study outcomes up to six years post SCI. However, the number of remaining patients and controls in Study 1 gradually decreased with increasing time after injury due to censoring (for example, reaching a 67th birthday). In the 6th year after injury, 45% of the patients and 47% of the control contributed with outcome data for the analysis. Differences in outcomes after many years after SCI must therefore be interpreted with some caution.

In the surveys in Studies 2 and 3 we asked people to take part in a study by filling out a questionnaire. Non-response is an important potential source of selection bias (volunteer bias) in survey research because those who choose to take part may differ fundamentally from those who choose not to take part. It is therefore important to examine the characteristics of responder and non-responder groups.

In Study 2 it was possible to compare the 339 persons who responded to those that did not since there was information on non-responders from the register data. The non-responder analysis showed that the baseline characteristics for the non-responders had only minor differences compared with the responders, giving little reason to believe that the relationships assessed in the study would differ for non-participants.

In Study 3 there was no data on the next of kin who did not respond. Furthermore, only 92 of the 339 persons with SCI provided contact information for their next of kin in Study 2 and, consequently, the final sample size in Study 3 was small (N=73). Results from Study 3 must therefore be interpreted with care, since we do not know which factors (patient and next-of-kin) influenced participation. It might be that persons with SCI with a poor relationship with their next of kin were less interested in providing contact information. In that case, we would expect the results presented in Study 3 to overestimate levels of QoL, due to the expected association between good relationships and higher QoL.

5.4.2 Information bias

Information bias describes the possibility of systematic errors that occur when the collected study information is wrong or misclassified (Rothman et al., 2008). Information bias is also called measurement error (Rothman et al., 2008) and may result from inaccuracy by the investigator or from poor quality of measuring or survey instruments.

The information needed to perform the three studies in this thesis was collected by data extraction from the registerers (NorSCIR, SSB, and NAV) and through the two surveys. Use of register data minimizes the risk of information bias, compared with patient-reported outcome measures (Hjollund et al., 2007). All three studies used data on independent variables on SCI injury characteristics from NorSCIR. The structured data collection in NorSCIR is based on the international SCI Data Sets (Biering-Sorensen et al., 2017). The centralised SCI care in Norway contributes to highly experienced SCI professionals performing consistent clinical evaluations and collecting data. Data quality is high due to regular quality assurance processes in NorSCIR to reduce missing, inconsistent, duplicate, and misclassified data (Halvorsen & Pettersen, 2022). Although data were pre-collected for purposes other than this research project, the data are considered to be highly reliable and valid. However, one limitation was that some patients had missing neurological status at discharge, and the use of neurological status at admission as a substitute may have been cause of misclassification.

Study 1 data from NorSCIR was linked to data from national registers (SSB and NAV) to assess work-related outcomes. Registry data from SSB and NAV is generally highly reliable, being the basis for all payments and cash transfers from the state (taxes and benefits). In general, misclassification of outcome status was therefore not a large problem in this study. Some variables, like pay for work, were available on an annual basis only, yielding less detailed information on the outcome in defined time intervals.

Studies 2 and 3 used data from surveys (questionnaires). One major limitation of self-reported data from surveys is that the accuracy of responses cannot be determined. The main strategy to prevent information bias is to use validated self-reporting instruments for data collection. Assessment of participation, QoL, and caregiving in Studies 2 and 3 was performed by using validated instruments (Al-Janabi et al., 2010; Geyh et al., 2010; Post et al., 2012; Robinson, 1983; van Exel, Scholte op Reimer, et al., 2004; van Leeuwen, van der Woude, et al., 2012). However, the measure used for "Types and frequencies of support" (called objective burden (Post et al., 2005)) has no published validation study. Nevertheless, it has been used in several other studies in the SCI population (Post et al., 2005; Eline W. M. Scholten et al., 2018) and is thus not likely to cause more information bias than the other validated questionnaires.

Another aspect of the measures used was that not all of them were available in Norwegian, and the translation could introduce biases. To reduce this, the translations were performed according to existing guidelines (World Health Organization, 2009).

Participants of survey 2 (patients) and survey 3 (next of kin) were asked not to discuss their answers on the survey with each other. Still, it was not possible to control whether or not they complied, and this might be a source for information bias. It may be possible that next of kin gave low scores on burden in order not to hurt their loved ones

Some missing data in the surveys may have caused information bias; however, the levels of missing information in the survey were modest and not regarded as a major problem in Studies 2 and 3.

5.4.3 Confounding

Confounding means the confusing of effects and implies a mixing of effects that may result from a factor (the confounder) that acts as a common cause of both the exposure and the outcome (Rothman et al., 2008). Potential confounders can be adjusted for in the analyses to reduce biased estimates.

For the association between injury and work participation over time in Study 1 we considered age, sex, and level of education as the most important potential confounding factors and adjusted for these variables in all regression models. In separate models we also included adjustment for other potential confounders, such as injury characteristics and pre-injury employment variables. In the comparison of labour market participation between patients with controls in Study 1 we chose to perform the analyses within matched groups, which means that it is automatically adjusted for the matching variables.

In Studies 2 and 3 the regression analyses were adjusted for what we considered to be possible confounding variables. These were sex, age group, education level, time since discharge group, cause of injury, and impairment group (neurological level and AIS) in Study 2, and age and sex in Study 3.

5.4.4 External validity

The knowledge generated in a research project, if valid, should be generalisable beyond those taking part in the study (external validity) (Hess & Abd-Elsayed, 2019; Rothman et al., 2008). To be able to so, the sample in the study should be representative of the population it is drawn from. As discussed in Section 4.3.1, Selection bias, the samples in Studies 1 and 2 were considered representative for the population they were drawn from, which is the population of persons with SCI and the general working population of persons with SCI in Norway. This could not be investigated in Study 3 (next of kin), meaning that the representativeness of this study to the whole population of next of kin to persons with SCI in Norway cannot be ascertained.

Another aspect of generalisability is the setting where the research took place. The studies in this thesis are performed in a Norwegian context, which must be considered when interpreting the results. The consequences of the study being done in Norway is that the external validity is limited to other similar countries. Similar countries in the context of this thesis are other developed countries with high standards of health care, specialized SCI units, and extended social security policies.

Although not directly about external validity in a strict sense, the inclusion criteria of the different studies should also be taken into consideration when applying the findings in other settings. Only persons with SCI that received pay for work in the year before injury were included in Study 1. This means that the findings in Study 1 are generalisable to patients with SCI who were working before injury. In Study 3 on next of kin, the inclusion criteria were designated as “A person who provides unpaid support, or the one who is closest to you. Usually it is a partner or other close relative such as parent, child, or sibling”. Thus, the findings from Study 3 might not be generalisable to next of kin falling outside of this category. Still, it should be noted that 73% of the next of kin were the partner of the person with SCI.

6 Discussion of the main findings

This thesis is about living with SCI among persons with SCI and their next of kin. The main objective of the included studies was to provide new knowledge about living with SCI, specifically on participation, QoL, and caregiving among persons with SCI and their next of kin. This chapter discusses and reflects on the main findings (presented in chapter 4), in the context of existing literature. The three main themes of this chapter are:

1. Living with SCI.
2. Modifiable and non-modifiable factors.
3. Impact of environmental factors.

Discussions of the specific findings in each study are provided in their associated papers.

6.1 Living with spinal cord injury

The studies in this thesis provide comprehensive information on persons living with SCI and their next of kin in the first eight years after injury.

Participation was a central theme in all three studies. Study 1 found that two out of three persons with SCI participated in the labour market six years after injury, at least to some extent. Still, this is lower than the control group, and aligns well with the finding in Study 2 that persons with SCI reported restrictions in performing vocational activities more often than other activities. Furthermore, the levels of participation were also lower than found among next of kin (Study 3).

Participation through having paid work, leisure-time activities, and good relationships with other people, has been found to be important for one's QoL, as pointed out in the introduction (Bickenbach, 2013). However, for people living with SCI, it may be more difficult to participate in such activities than it is for people without health problems. A strong association between participation and QoL was found in Study 2, which is known from other studies (van Leeuwen, Kraaijeveld, et al., 2012) and from other fields (Lund & Lexell, 2009). 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 leisure activities. Furthermore, next of kin of persons with SCI may experience limitations to participation due to their caregiver role. However, Study 3 showed that four out of five next of kin rated good or very good QoL, which is in contrast to what has been reported in previous international research (Lynch & Cahalan, 2017).

Persons with SCI (Study 2) reported lower levels of QoL than next of kin (Study 3) and were especially dissatisfied more often with health and daily activities. A Dutch study found no differences in levels of mental health and life satisfaction between persons with SCI and their partners (E. W. M. Scholten et al., 2018). However, the Dutch study only included couples. Still, a difference between the person with SCI and next of kin could be due to having an injury. However, the severity of SCI (neurological level and completeness) did not influence QoL in neither persons with SCI nor in next of kin (Studies 2 and 3). This is also in line with other studies among persons with SCI, which concluded that differences in QoL are not well predicted by the severity of the injury (Post & van Leeuwen, 2012; Rivers et al., 2018; Tate et al., 2002; van Leeuwen, Hoekstra, et al., 2012), but more likely predicted by other factors such as secondary health conditions (Lidal et al., 2008; Putzke et al., 2002; van Koppenhagen et al., 2008). However, the majority of family caregiver studies highlight, in contrast to Study 3, severity of injury as a factor that may negatively impact caregiver QoL, with greater depression noted in caregivers of more severely injured patients. In summary, personal factors, such as income and education, were found to have greater impact on participation and QoL in persons with SCI and next of kin, rather than the severity of the injury.

The need for informal care provided by next of kin for persons with SCI is increasing due to the increasing life expectancy of the individuals with SCI (Strauss et al., 2006) and the strain on the public sector budget (Lipszyc B, 2012). Study 3 is the first Norwegian study to report on burden of care, participation, and QoL of next of kin of persons with SCI. Although most next of kin were happy to provide support, one-quarter reported high levels of strain, especially related to emotional adjustments. Next of kin experiencing high levels of caregiver strain may have far-reaching adverse consequences (Scholten, 2020). Their own health, functioning, and psychosocial well-being can be compromised, as well as that of the individuals with SCI they are supporting (Kokorelias et al., 2019). This has been acknowledged by the Norwegian government, which has made it clear that the contribution from informal carers is vital for the welfare system and that it is important not to create new patients or have carers falling out of employment (Ministry of health and care services, 2020). A national strategy for carers with a plan of action for the coming years was published in December 2020 (Ministry of health and care services, 2020). One of the main goals in the plan is to "to appreciate and value the contribution from informal carers", and this is likely to be valued by next of kin supporting persons with SCI.

6.2 Modifiable and non-modifiable factors

Factors that influence the outcomes in this thesis - like participation, QoL, and caregiving - can be divided into those that are modifiable and those that are not (Trenaman et al., 2015). Modifiable factors may be amenable to interventions, either through improvement or through preventing deterioration. Some examples of modifiable factors are secondary health conditions, mobility, wheelchair skills, accessibility, personal attitude, and post-injury education. Non-modifiable factors are also important to study because they can help identify groups at risk. Some examples of non-modifiable factors are aetiology of injury, severity of injury, pre-injury employment, pre-injury education, sex, and age.

It was an interesting finding that the impact of non-modifiable SCI characteristics on different life areas was limited. SCI severity (level of injury and completeness) was found to influence labour market participation, restrictions in participation among persons with SCI (Studies 1 and 2), and the self-reported objective burden of care among next of kin (Study 3). On the other side, life satisfaction and mental health reported by patients with SCI (Study 2) and their next of kin (Study 3), were less influenced by SCI severity. Furthermore, subjective caregiver burden reported by next of kin in Study 3 was not affected by SCI severity. Notably, next of kin of persons with less severe impairment (paraplegia AIS D) tended to report almost similar results for subjective burden of care compared with next of kin of persons with more severe impairment (tetraplegia AIS A–C).

It was found that higher level of education was associated with higher levels of life satisfaction, participation, and labour market participation (Studies 1 and 2). This is in line with findings in previous research (Edgerton et al., 2012; Gross-Hemmi et al., 2019; Ottomanelli & Lind, 2009; Statistics Norway, 2020). Level of education is a factor that can be modified after the injury, as also pointed out in the discussion in Studies 1 and 2. Informing patients with SCI - especially younger persons with a new SCI - of the positive effect of higher education during primary rehabilitation and encouraging them to return to school and further education is thus justified. Furthermore, higher educated persons are more often in non-physically demanding employment compared to those with lower education (Schwegler et al., 2021). Persons with higher education post-SCI therefore have more career opportunities open to them (Schwegler et al., 2021). This indicates that promoting vocational re-training towards jobs requiring higher education is likely to be a reasonable approach to increase the level of labour market participation (Schwegler et al., 2021; Sturm et al., 2020). Furthermore, in case of severe neurological outcome, it is important to consider interventions to improve mobility, such as assistive technologies or adaptions in the environment (living places and workplaces).

Increased employer incentives, such as obligations regarding offering a suitable job and providing workplace adaptations, could also be useful to increase labour market participation (Hemmings & Prinz, 2020). Previous research has indicated that the role of the employers is underutilised in Norway (Solheim & Leiulfsrud, 2018).
Several other modifiable factors that may influence participation and QoL have been described in literature, such as the prevalence of secondary health conditions (e.g., pressure sores, urinary tract infections, pain, and fatigue) (Adriaansen et al., 2013; Meade et al., 2011), accessibility (Whiteneck et al., 2004), and psychological (Peter et al., 2012) resources. Those factors were not explored in this thesis.

As mentioned above, SCI severity was found to primarily influence objective performance (labour market participation, participation, and caregiving) (Studies 1-3) and, to a lesser extent, subjective experiences (QoL and caregiver burden) (Studies 2 and 3). One way to explain this could be the so-called "response shift" described by Sprangers and Schwartz (Sprangers & Schwartz, 1999). A "response shift'" is a change of internal standards and values and the conceptualization of QoL (Sprangers & Schwartz, 1999). Both patients and next of kin confronted with a SCI are faced with the necessity to adapt to their "new life". Thus, they undergo an adaptation process. This may explain why participants seem to report consistently on questions about their functional status or employment over time, while the relative importance they place on these answers, and thus their satisfaction, often changes for the better over time (Sakakibara et al., 2012; Tate et al., 2002).

6.3 Impact of environmental factors

Environmental factors are the external circumstances that can influence us. In the ICF model disability is seen as the outcome of a complex relationship between the external factors of the environment in which he or she lives, the individual's health condition, and personal factors (Goering, 2015). Thus, environmental factors interact with health conditions (e.g., SCI) and influence the experiences of disability. In the ICF model environmental factors are covered by the following domains: 1) products and technology, 2) natural environment and human-made changes to environment, 3) support and relationships, 4) attitudes, and 5) services, systems,

and policies (World Health Organization, 2002). These factors are often modifiable, although not always within the person's control. Improvement of those factors in society may contribute both to reducing disability and promoting participation and QoL.
In this thesis "support and relationships" (domain 3), and, to some degree, "services, systems, and policies" (domain 5) of the environmental factors in the ICF are investigated. The use of sickness and disability benefits to compensate for income loss is covered by domain 5 (Study 1), and the role of the next-of-kin is covered by domain 3 (Study 3).

In Study 1, receipt of sickness and disability benefits was a measure that provides some information about how the social security system in Norway, which can be considered as an environmental factor, works for persons with SCI. The study showed that 67% of the patients with SCI who received pay for work in the year before injury, received sickness and disability benefits six years after injury, often in addition to some income from work (Study 1). This finding on its own was not that surprising because it is known that the use of sickness and disability benefits in Norway is high in comparison with other countries (Norwegian Ministry of Labour and Social Affairs, 2019). This can be due to the rather generous social security system acting as a supportive environmental factor, as it offers basic income up to 400.000 NOK / 40.767 EUR (depending on previous income) for those who are not or less able to be self-supporting. In a recently InSCI study on the experience of environmental barriers by people with SCI across 22 countries (Reinhardt et al., 2020), results showed that most barriers were experienced in relation to accessibility, climate, transportation, finances, and state services (Reinhardt et al., 2020). This confirms the importance of social security system, as discussed in the publication from Study 1. Still, the high consumption of benefits could be seen as worrying as it might mean that it replaces an effort to ensure as high as possible long-term employment.

This argument is supported by the finding in Study 1 that the proportion of patients receiving pay for work and receiving sickness and disability benefits reached a steady state after approximately 3-4 years. The timing of this turning point could reflect the characteristics of the Norwegian benefit system, allowing a maximum one year of sickness benefits and three years of work assessment allowance (description in chapter 3.2.2). Transforming disability benefits into an employment instrument has been recommended by the OECD for several years (OECD, 2010). However, it has recently been discussed that sickness absence and disability benefit recipiency levels remain extraordinarily high in Norway compared to other countries such as Sweden, Switzerland, and the Netherlands (Hemmings & Prinz, 2020). Broadly speaking, it is argued that Norway has fewer measures involving reductions to entitlements and improvements in work incentives compared with those other countries (Hemmings & Prinz, 2020). This aligns with an InSCI study that investigated how performance of the health system in 22 countries are linked to QoL, which suggested that Norway should put more effort in access to vocational rehabilitation to further improve the QoL of people with SCI (Pacheco Barzallo et al., 2020).

Vocational rehabilitation and rapid work-related engagement through early intervention has been identified as beneficial for the return-to-work process in the first two years in patients with acquired brain injury (van Velzen et al., 2016). There are signs of increased attention to early vocational rehabilitation after SCI (Dunn et al., 2021; Holmlund et al., 2020). Still, during the post-acute rehabilitation phase there are a number of challenging issues that need to be handled, like unclear prognosis, complex diagnosis, other rehabilitation goals, limited time, and patients needing to adapt to their new situation. However, delayed or fragmented support for labour market participation may result in less people with SCI participating in the labour market in the long term (Holmlund et al., 2018).

Thus, it is likely that work participation needs to be more in the forefront of the ongoing activities, and not just a long-term goal that can be dealt with later. Having more and earlier focus on labour market participation may result in more people with SCI participating in the labour market, consequently lowering the proportion of those who need sick leave/disability pension. Thus, the SCI units could take a stronger role in promoting work participation. All three SCI units in Norway have a commitment to life-long follow-up for persons with SCI (Strom et al., 2017). Discussing work related issues with the patients and having contact with the employer as early as possible would give an excellent opportunity for increased involvement in employment participation issues by the rehabilitation team in the long term.

7 Conclusion

This thesis shows that the majority of persons with SCI and their next of kin living in Norway are doing quite well in important life areas. Groups at risk for low outcomes regarding participation, QoL, and caregiver burden were identified. It seems that environmental factors have more impact on participation and QoL than SCI on its own.

The most important goal of rehabilitation is to enable disabled people to return to independent and satisfying lives in the community. The findings of this thesis, together with prior research, imply that the SCI rehabilitation team should, in addition to health interventions, focus on vocational rehabilitation, creating participation opportunities, environmental adaptations, and social and emotional support with a lifelong perspective to support the everyday life of persons with SCI and their next of kin.

8 Implications for practice

Based on the findings and the literature, some suggestions for how the knowledge can be used in the practice field is offered. Study 1 gives an updated and methodologically strong account of labour market participation among persons with SCI. Seen together with the findings in Study 2 confirms the notion that being part of the work force is important. Thus, potential consequences of the injury on labour market participation should be discussed with the patients as early as possible. This includes a strong emphasis on vocational rehabilitation as well as preparation towards jobs requiring higher education. This requires that the healthcare professionals at the SCI units be well educated in vocational rehabilitation (Roels et al., 2020). In addition, more flexible workplace adaptations and more employer incentives should be considered to increase labour market participation for patients with SCI.

As a consequence, the SCI rehabilitation team could take the lead in drawing up a plan for reintegration into the workforce before discharge from the SCI rehabilitation department, supported by the patient, employer, and all professionals involved in the reintegration process. Person-centred interventions coordinated by a designated coordinator, job-matching tools determining suitable target jobs, and planning interdisciplinary intervention for labour market participation of persons with SCI may be helpful (Holmlund et al., 2020; Nutzi et al., 2020).

Work related outcome variables in quality registers could be helpful in providing high quality knowledge that could be used by the practice field concerning employment efforts for persons with SCI. One possible action for NorSCIR could be to consider including a set of measures on employment structure, process, and outcome indicators that have recently been developed in Canada (Alavinia et al., 2021).

In some cases it is too premature to focus on labour market participation during the first year(s) after the injury. For these persons, a renewed attempt in creating labour market participation should be encouraged later on, even if it is made several years after the initial rehabilitation period. Thus, the SCI rehabilitation team should keep employment participation issues in mind in the long term as well (Image 2).

Image 2. Multidisciplinary meeting with a person with SCI, employer, colleague, representative of NAV, career advisor of JobLearn (a work inclusion company), and a member of the SCI team. The goal of the meeting was to plan labour market participation eight years after the initial rehabilitation period.
(*Image with permission from all participants*).

Focus on non-vocational activities are also required, especially in situations where work integration is not relevant or possible. This may become even more important due to ageing in the SCI population, which leads to an increased number of retired persons living with SCI. A Swedish study showed that those who lived 36–55 years after SCI often had secondary complications such as pain, fatigue, and spasticity, which negatively affected participation in activities (Lundstrom et al., 2017). Concerns in relation to personal assistance, assistive devices, and rehabilitation were reported (Lundstrom et al., 2017).The SCI rehabilitation team thus needs to pay attention to participation in leisure activities in the long-term follow-up because living situations of the person with SCI may change over time.

The contribution from next of kin as informal carers is vital. The Norwegian Carers Strategy suggestions how to improve the support of the informal carers without simple solutions (Ministry of health and care services, 2020). It is just as important that the SCI units take responsibility for how they can best contribute in the follow-up of the next of kin of persons with SCI. Examples of actions are early identification of caregiving challenges, education, and guidance. To reduce the subjective burden of care, it seems necessary to increase the ability of some of the next of kin to cope with the emotional challenges related to their caregiver role. Interventions, such as caregiver counselling and peer support groups, could be useful to achieve this. Strengthening the experience of positive aspects of caregiving may also enhance better mental health for the next of kin. This emphasises the importance of regularly monitoring the burden among next of kin in order to detect problems. The Caregiver Strain Index (CSI) (Robinson, 1983) used in Study 3 seems a useful tool that is easy to administer during regular follow-up visits and quickly gives an indication of perceived burden.

9 Suggestions for future research

Future research should include several prospective studies concerning the process of reintegration into society after SCI, with regard to both people with SCI and their next of kin.

Linking clinical data with national registers should be used more. Such a linkage has proven feasible, e.g., as demonstrated in Study 1, and gives long-term functional outcome information with high validity and completeness. One example could be a study linking data from NorSCIR and the Norwegian Cause of death registry, which could provide useful information on long-term outcome after SCI.

Identification of different subgroups of individuals with SCI who experience problems in the reintegration process after SCI can improve the quality of individual counseling and the use of effective interventions and strategies. This can, for example, be done by studying the impact of secondary health conditions, psychological personal factors, and several environmental factors on participation and QoL of persons with SCI. Such research would also benefit from combining register data and patient/next of kin reported outcome data.

SCI may also influence the work participation among next of kin, due to their caregiver role. This could be investigated in a study that links data from next of kin of persons with SCI to the SSB and NAV registries.

Finally, clinical trials on the effect of interventions developed to increase return to work after SCI (Holmlund et al., 2020; Nutzi et al., 2020) could contribute to more knowledge of efforts to increase labour market participation.

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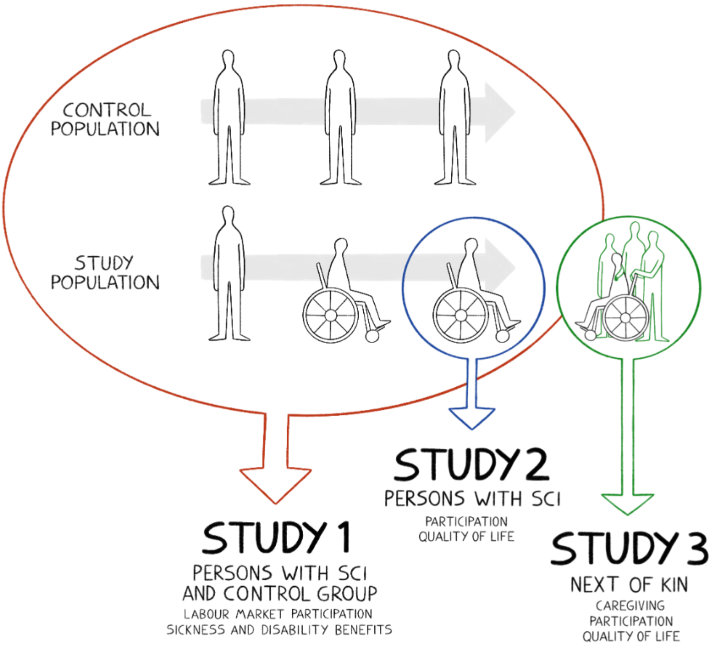
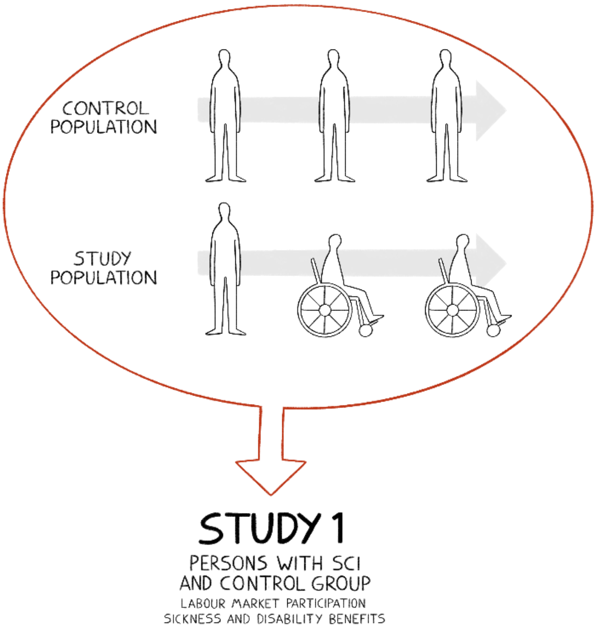
11 Papers I-III



Paper I


CONTROL POPULATION
STUDY POPULATION
STUDY 1
PERSONS WITH SCI AND CONTROL GROUP
LABOUR MARKET PARTICIPATION
SICKNESS AND DISABILITY BENEFITS

Title page

Title of the paper:

Labour market participation after spinal cord injury. A register based cohort study.

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Abstract

Study Design: A register based cohort study.

Objectives: To investigate labour market participation following spinal cord injury (SCI) compared to a matched sample from the general population, and to describe the impact of personal and SCI characteristics on labour market participation.

Setting: Norway.

Methods: Patients receiving pay for work (>0 NOK/EUR) in the year before SCI, were matched with controls and followed for up to six years after injury. Main measures of labour market participation were: 1) Receiving any amount of pay for work, and 2) Receiving sickness and disability benefits.

Results: Among patients with SCI who received pay for work in the year before injury (n=451), 63% did so again six years after the injury, and an equal percentage (67%) received sickness and disability benefits. For the controls (n=1791), the corresponding levels were 91% and 13%. Patients with SCI with less severe neurological outcome, higher level of education, younger age at injury, and a stronger pre-injury attachment to employment (higher employment income, having an employer, less receipt of benefits), were more likely to have higher labour market participation.

Conclusion: SCI substantially decreased labour market participation during up to six years after injury, especially among the more severely injured and low educated patients. Even if a relatively large proportion of patients with SCI remained in some degree of work activity, more than half did so in combination with receiving benefits.

Introduction

Employment is a key rehabilitation outcome for people with spinal cord injury (SCI), and it tends to be positively associated with adjustment to SCI, life satisfaction, a sense of purpose, mental stimulation, social contact and well-being [1]. The level of employment among people with SCI is positively influenced by a number of factors, such as personal factors (younger age at time of injury, higher level of education, higher motivation), SCI-related characteristics (less severe neurological outcome) and employment-related factors (support from the employer, possibility to continue working in the same organisation) [2-6].

Most people with SCI can potentially be in employment if they get access to appropriate work accommodations [1]. However, the average employment rate among 9875 patients with SCI in 22 countries across the world was 38% (ranging from 10% to 61%), which was considerably lower than in the respective general working populations [7]. Contextual country-level factors, such as labour market systems and policies with respect to social security, vocational rehabilitation and employment, may explain some of the differences in employment levels across countries [8].

Norway has a well-developed welfare and health care system with universal rights to health and welfare provisions, a strong policy emphasis on high employment, and high expenditure on return to employment measures after sickness or injury. Compared with other European countries, a large portion of the Norwegian population is on sickness and disability benefits [9]; 17% in the 18-66 age group [10]. Still, in the last quartile of 2021, 72.3% of the population was part of the work force [11]. The proportion employed following SCI in Norway have been reported to range from 35% to 52% in different studies [4, 5, 7, 12], which shows that there is considerable employment gap between patients with SCI and the general population.

To gain further knowledge regarding labour market participation in the SCI population, there is a need for longitudinal studies with information on both employment and sickness and disability benefits, to achieve a more complete picture [13]. Norway is an ideal place to perform such studies due to its national SCI registry which can be linked to several population-based databases [14].

The overall objective was to investigate labour market participation up to six years following SCI compared to a matched sample from the general population. The specific aims were: 1) to describe labour market participation post SCI for patients receiving pay for work (>0 Norwegian Kroner (NOK) / Euro (EUR)) the year before SCI; 2) to compare labour market participation following SCI with a control group from the general population; 3) to describe the impact of personal and SCI characteristics on labour market participation after SCI.

Methods

Study design

Cohort study following patients with SCI from the Norwegian SCI registry (NorSCIR) and a matched control group taken from the general Norwegian population for one year before injury and up to six years after using national registry data on employment, education, income, and social security benefits.

Ethical approval was obtained from the Regional Committee for Medical and Health Research Ethics in Central Norway (2018/294/REK-midt). Registration in the NorSCIR is voluntary with a written informed consent before registration occurs. Annual reviews show that this registry covers > 90% of the incidence population [15]. Patients giving consent to participate in NorSCIR accept that their information can be used for research purposes, including linkage with a range of national registers.

Study samples

The inclusion criteria for the SCI sample, were all patients who experienced traumatic or non-traumatic SCI, were admitted to one of the three SCI units in Norway and registered in the NorSCIR from 01.01.2011 to 31.12.2017, were in working age (16 to 66 years) at time of injury, living in Norway in the month before injury, and who received pay for work (>0 NOK/EUR) in the year before SCI. We used 66 years of age as the upper limit because the legal retirement age is 67 years in Norway. The lower limit of 16 years was chosen as this is the last year of compulsory education.

A control sample was randomly drawn from the general population by Statistics Norway, matching the SCI sample for year of birth, sex, county of residence, and level of education. Five controls were drawn for each patient. Only controls living in Norway and employed, according to the same definition as for the SCI sample, were included in the analyses.

Data sources

NorSCIR [16] provided information on personal and injury characteristics: Age at injury, sex, date of acute hospital admission, neurological classification and cause of injury.

Statistics Norway (SSB) [17, 18] provided data on income from work, registration status (dates of death and emigration), highest attained educational level, ongoing education, year of birth, county of residence, and sex (controls).

The Norwegian Labour and welfare administration (NAV) [19, 20] provided information on dates of sickness absence benefit, work assessment allowance, disability pension, old age pension, and employment status.

The Norwegian social security system

All persons who are either residents or working as employees in Norway are insured under the National Insurance Scheme, managed by NAV [19]. Employed people can be granted sick leave compensation covering up to 100% of income for a period of maximum 52 weeks if they are unable to work due to an illness or injury. After 52 weeks, employees with a reduction in work ability of at least 50 percent due to illness or injury may apply for long-term benefits (work assessment allowance (AAP) or disability pension (DP)) to compensate for loss of income. While AAP is a temporary benefit (max 3 years) requiring active treatment and/or rehabilitation measures, DP is granted on a permanent basis to those whose earning capacity is permanently reduced. The total allowance from AAP and DP is approximately 66 % of the income from the three best payed of the last five years before disability and up to maximum six times the National insurance basic amount (G) for each year (1G=106 399 Norwegian kroners, approximately 11 033 euro (as of 21.3.2022)).

Linkage

The SCI and control sample were linked to the various registry data by an identification key created by Statistics Norway using the unique 11-digit personal identity number given to all Norwegian citizens.

Follow-up period

The start of the follow-up period was 12 months before the date of injury. The date of injury was set to the date of acute hospital admission registered in NorSCIR for the SCI sample, and controls were assigned the same date as their respective matched SCI patients. Participants were censored at the date/month of emigration, death, 67 years' birthday, last available data (31.12.2020) or month 72 after injury, whichever came first. The total follow-up period was divided into a maximum of seven 1-year time intervals (-1 (year before injury), 0-1, 1-2, 2-3, 3-4, 4-5, 5-6 (years after injury)).

Measures of labour market participation post spinal cord injury

Main measures of labour market participation post SCI were : 1) Receiving any amount of pay for work (>0 NOK/EUR), and 2) Receiving sickness and disability benefits, which included sickness absence benefit, work assessment allowance and/or disability pension, to compensate for loss of income. Additional outcomes included: 1) Mean employment income as a continuous variable and 2) Each of the sickness/disability benefits separately (Table 1).

PLEASE INSERT TABLE 1 APPROXIMATLY HERE

Study variables

Study variables included sex, year of birth, age at injury (16-29, 30-39, 40-49, 50-59, 60-66 years), county of residence, educational level (primary, secondary, higher education), employment income before injury (NOK 0-299.999, 300.000-499.999, 500.000-999.999, and ≥1.000.000) and employment status in the year before injury (having a registered employer for at least 9 out of 12 months or not), date of acute hospital admission for SCI ("2011-2014", "2015-2017"), cause of injury (traumatic, non-traumatic), and neurological status.

Categorisation of neurological status was done using the International Standards for Neurological Classification of SCI [21], including neurological level of injury and American

Spinal Injury Association Impairment Scale (AIS) grade, to create four SCI impairments groups (level and AIS): Tetraplegia (C1-C8) AIS A, B or C; Tetraplegia (C1-C8) AIS D, Paraplegia (T1-S5) AIS A, B or C; Paraplegia (T1-S5) AIS D, E. In cases of missing neurological status at discharge, this was replaced with the classification at admission. Those with AIS E at discharge had neurological level at T1 or lower prior to the last examination and were categorized into group Paraplegia AIS D, E.

Statistical analysis

Characteristics of the patient and control samples were presented with descriptive statistics.

We explored the association between time during follow-up and labour market participation using general estimation equations' (GEE) logistic regression analyses. Analyses included time as year in relation to injury (each year as a category, from year before to sixth years after) and repeated measures of the two dichotomous labour market participation outcomes (pay for work and sickness/disability benefits, assessed each year of follow-up for each participant). We performed separate analyses for the SCI and control samples, with adjustment for age, sex, and educational level. Estimates from the analyses were used to calculate and graphically present the level (percentage) of labour market participation at each 1-year interval during follow-up.

For the SCI sample, we used a similar approach to assess labour market participation over time for subgroups of age, sex, level of education, SCI impairment, and cause of injury. A separate GEE analysis was performed for each grouping variable by including it in the GEE model and adding an interaction term with the time variable. All analyses were adjusted for age, sex, and level of education.

For patients with SCI, we further explored the impact of various personal and SCI characteristics on labour market participation after injury using three different models (GEE logistic regression, with six repeated outcome assessments; from injury to six years after). Model A included adjustment for time, age group, sex, and level of education, Model B included additional adjustment for injury variables (SCI impairment group, cause of injury, year of injury), and Model C further added adjustment for pre-injury employment (employment income, employment status and medical benefits before injury).

We compared labour market participation between SCI patients and controls within matched groups using fixed effect logistic regression models. This analysis compares patients only with their designated controls, automatically adjusting for year of birth, sex, county of residence, and level of education (matching variables), and also accounting for the unequal number of controls per patient in the total samples. Estimates from the analyses were used to calculate the absolute and relative difference (prevalence difference in %-points and odds ratio with 95%CI) between the SCI and control sample for labour market participation at one year before injury, 1-3 years after injury and 4-6 years after injury.

Supplementary analyses included alternative outcome measures for labour marked participation (assessed each year of follow-up for each participant); 1) Mean employment income as a continuous variable (SCI and control samples) and 2) each of the sickness/disability benefits separately; sickness absence benefit, AAP and DP (SCI sample only). The association between time (year in relation to injury) and each outcome was analysed using GEE linear or logistic regression, with and adjustment for age, sex and education.

Stata® version 16.0 (StataCorp, College Station, Texas, USA) was used for all statistical analyses.

Results

Of the 751 patients registered in the NorSCIR from 01.01.2011 to 31.12.2017, 300 patients were excluded (aged ≥ 67 (N=179), pay for work = 0 (N=113), not living in Norway (N=8)). Thus, 451 patients with SCI met all inclusion criteria for this study.

After excluding controls aged ≥ 67, not living in Norway, and with pay for work = 0 (same criteria as for the SCI sample), 1791 persons matched to 443 SCI patients remained. In the SCI sample, 8 patients had no controls, 12 patients had one control, 33 patients had two controls, 68 patients had three controls, 141 patients had four controls and 189 patients had five controls.

The SCI and control samples were quite similar regarding age, sex, and education (Table 2). Controls had a slightly higher annual employment income and received less sickness and disability benefits during the year before SCI compared with the patients with SCI.

PLEASE INSERT TABLE 2 APPROXIMATLY HERE

As there were shorter follow up for those with injuries in the later years, the number of remaining patients and controls gradually decreased with increasing time since injury. In the 6th year after injury, 202 SCI patients (45%) and 841 controls (47%) contributed with outcome data for the analysis. The median follow-up time for the patient sample was 57 (IQR 38-72) months, and 58 (IQR 42-72) months for the controls (data not presented).

The estimated percentage receiving pay for work in the SCI sample gradually decreased from 100% before injury to 63% (95% CI 57-69) six years after injury, while decline in the control sample was from 100% to 91% (95% CI 90-93) (Figure 1a). The estimated percentage receiving sickness and disability benefits in the SCI sample was 18% before injury (95% CI 14-21), peaked to 87% during the first year after injury and then decreased to 67% (95% CI 61-72) six years after injury (Figure 2a). In the control sample it rose from 8% before "injury" to 13% (95% CI 12-15) six years later. The development of labour market participation over time for the SCI sample across subgroups (age, sex, educational level and injury characteristics) is shown in Figures 1b-f and 2b-f.

PLEASE INSERT FIGURES 1 APPROXIMITLY HERE

PLEASE INSERT FIGURES 2 APPROXIMITLY HERE

For the SCI sample, there was a gradual shift from short-term to long-term benefits during follow-up, with over half of SCI patients on disability pension (DP) at end of follow-up (Figure 3).

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Among those receiving pay for work 4-6 years after SCI, 55-57 % also received sickness and disability benefits (Supplementary Table 1).

Comparison between the patients with SCI and their controls (within matched groups) showed that patients had 28%-point lower annual percentage of receiving pay for work 4-6 years after SCI, and a corresponding 36%-point higher annual percentage of receiving sickness and disability benefits (Table 3).

PLEASE INSERT TABLE 3 APPROXIMATLY HERE

There were lower odds for labour market participation for those with higher age at injury (age 60+), primary level of education and more severe neurological outcome (tetraplegia AIS A-C) (Table 4). Compared with patients with less impairment (Paraplegia AIS D-E), patients with more severe impairment (Tetraplegia AIS A-C) had 70 % lower odds for receiving pay for work (OR 0.30, 95% CI 0.17-0.54, Model C), and about 20 times higher odds of receiving sickness and disability benefits (OR 19.6 95% CI 9.04-42.53 Model C). Differences in pre-injury employment (employment income, employment status and receipt of benefits) had a major influence on outcomes of labour participation after injury (Table 4).

PLEASE INSERT TABLE 4 APPROXIMATLY HERE

Results of the supplementary analysis are shown in supplementary figure 1 and Supplementary table 2.

Discussion

Summary of findings

Among patients with SCI who received pay for work (>0 NOK/EUR) the year before injury, two out of three did so six years after the injury, and an equal proportion received sickness and disability benefits. For the control group from the general population, the corresponding levels were nine out of ten receiving pay for work and one out of eight receiving sickness and disability benefits. Patients with SCI with less severe neurological outcome, higher level of education, younger age at injury, and a stronger pre-injury attachment to employment, were more likely to have higher labour market participation during the years after injury.

Study strengths and limitations

Strength of this study is the nationwide register-based and controlled design, with clinical patient data from a national medical SCI quality registry linked with complete individual national registry data on employment, education, income, and social security benefits. This linkage provides high accuracy and quality owing to the use of the unique identity number assigned to all Norwegians. Use of registry data minimizes the risk of information bias, compared with patient-reported outcome measures [22]. Moreover, we had access to data of the general population and could therefore provide a detailed comparison between people with SCI and the general population.

There are some noteworthy limitations. Only patients that received pay for work in the year before injury were included in this study, which means that the results are not generalizable to all patients with SCI. Furthermore, the number of control persons per patient varied from zero to five, introducing some imbalance in the composition of the control sample. The comparisons between the SCI sample and control sample must therefore be interpreted with caution. However, we have taken this imbalance into account by performing analyses within matched groups. The outcome pay for work is based on annual registrations, with the consequence that those with SCI are registered with income the year of their injury.

Level of labour market participation post SCI

The proportion receiving pay for work among patients with SCI was 28%-points lower compared with their matched controls from the general population. Thus, as expected, this study confirms the common notion and earlier studies showing that a SCI injury reduced labour market participation [2]. Conversely, the proportion receiving sickness and disability benefits among patients was 36%-point higher than their matched controls.

Our finding that 63% received pay for work six years post injury is higher than the level reported from most other studies from Norway (35% to 52%, [4, 5, 7, 12]) and internationally (10% to 61% [7]). However, these studies have used different definitions of work activity, preventing a direct comparison, a problem that has been reported in literature reviews [2, 13, 23]. A recently published systematic review showed that 54 % of the studies used a salary-dependent definition such as “working for pay” or “earning minimum wage” [13]. The definition used in our study, being registered in the tax system as receiving any pay, was inclusive and led to a higher level than e.g. a definition of including those earning more than the minimum wage would have given. Thus, the proportion who received pay for work in our study was on the high end, but the relative difference to the general population was not influenced as the same definition was used.

When it comes to the level receiving sickness and disability benefits, which was 67% after 6 years post injury in our study, there are similar challenges regarding direct comparison. For previous studies with linkages to national registries, the levels reported have been 41 % 5 years after severe trauma in Norway [24], and 24% 5 years after mild traumatic brain injury in Denmark [25]. In our study, the high post-injury level of benefit receipt was probably partly influenced by the pre-injury level of sickness and disability benefits in the SCI sample (17 %), which was elevated compared to controls (9%). This difference in pre-injury benefit status is in line with findings from a nationwide Danish register-based SCI study that showed approximately two times higher health care costs for patients with SCI two years before injury, compared to controls [26]. We found their explanation, that this might be related to ongoing disease in advance of non-traumatic SCI, and a traumatic SCI group that could be more accident-prone, both resulting in higher costs, plausible and relevant for our findings.

Increasing labour market participation

Even if the current study showed a relatively high level of labour market participation for patients with SCI, efforts should be made to increase it further, especially because a considerable group is not included in the labour market after SCI (mainly the more severely injured and low educated patients). At the same time, the importance of work in people's lives is well known [1, 27].

The factors found in this study to influence labour market participation following SCI, neurological outcome, level of education, age at injury, time since injury, and pre-injury attachment to employment, strongly confirming findings from previous studies [2-6]. Of these, gaining additional education is a factor that can be modified after the injury [3]. Higher educated persons are more often in non-physically demanding employment compared to those with lower education [28]. Consequently, persons with higher education post SCI tend to have more career opportunities open to them [28]. Thus, promoting vocational re-training towards jobs requiring higher education is likely to be a valid approach to increase the level of labour market participation [28-30].

But also measures taken at the workplace should be considered. One example is assistive technologies which have been suggested to be helpful for those with limited cognitive resources to do physically oriented jobs [28]. Also increased employer incentives, such as obligations regarding offering a suitable job and providing workplace adaptations could be useful [9]. Previous research has indicated that the role of the employers is underutilised in Norway [5].

Conclusion

Labour market participation clearly decreased after injury among patients with SCI. Even though a relatively large proportion of those who participated in the labour market before SCI still did so after injury, more than half of these also depended on sickness and disability benefits. Even stronger emphasis of vocational re-training towards jobs requiring higher education, more flexible workplace adaptations and more employer incentives should be considered to increase labour market participation for patients with SCI.

Data availability

The data used in this study are from the NorSCIR, SSB and NAV. There are restrictions on the use of data from national registries. These data were used under licence for the current study and are not publicly available.

Acknowledgements

The authors thank user representatives Monica Engelsjord, Anders Nupen Hansen, and Steinar Mikalsen for using their personal experiences to give input on the study design and for reporting the results. We further thank the three SCI specialized centers, located at Haukeland University Hospital, St Olav’s University Hospital, and Sunnaas Rehabilitation Hospital, for registration in NorSCIR, the steering committee of the Norwegian SCI registry (NorSCIR) for providing access to the data, and Ann Louise Pettersen for delivering the data.

Statement of Ethics

Ethical approval for this study was obtained from the Regional Committee for Medical and Health Research Ethics in Mid Norway (2018/294/REK-midt). We certify that all applicable institutional and governmental regulations concerning the ethical use of human volunteers were followed during the course of this research.

Conflicts of Interest

The authors declare that they have no conflict of interests. AH is the leader of NorSCIR but had no role in granting access to or delivery of the NorSCIR data.

Authors' Contributions

AH was the main investigator of the study and the main contributor in the writing of the paper.

AH, KP and AS were responsible for designing the study with support from MP and FBS.

AH was responsible for the data collection.

AH and KP analysed and interpreted the data.

AH, KP and AS prepared and revised the drafts of the manuscript.

ASL, MP and FBS provided feedback on the manuscript.

All authors have given their final approval of the version to be submitted.

Funding

The funding for the research project which this study was part of came from 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).

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Table 1. Description of measures of labour market participation

Main outcomes	Data source	Variable(s)	Construction	Assessment periods
Receiving any amount of pay for work	SSB(17, 18)	Any income from work and self-employment. (Annual observations)	Receiving pay for work (pay for work>0 NOK/EUR) (1) or not receiving pay for work (no pay for work) (0).	1-year intervals from date of injury to six years (72 months) after injury.
Receiving sickness and disability benefits	NAV(19,20)	1. Sickness absence benefits. 2. Work assessment allowance. 3. Disability pension. (Monthly observations)	Receiving any of the three benefits (1) or not receiving any benefit (0).*	1-year intervals from one year (12 months) before injury to six years (72 months) after injury.

Additional outcomes	Data source	Variable(s)	Construction	Assessment periods
Employment income	SSB(17, 18)	Income from work and self-employment. (Annual observations)	Level of employment income (in NOK(EUR)) as continuous variable	1-year intervals from one year before injury to six years (72 months) after injury.
Receiving sickness absence benefit	NAV(19,20)	Sickness absence benefit. (Monthly observations)	Receiving the benefit (1) or not receiving the benefit (0).*	1-year intervals from one year (12 months) before injury to six years (72 months) after injury.
Receiving work assessment allowance	NAV(19,20)	Work assessment allowance. (Monthly observations)	Receiving the benefit (1) or not receiving the benefit (0).*	1-year intervals from one year (12 months) before injury to six years (72 months) after injury.
Receiving disability pension	NAV(19,20)	Disability pension. (Monthly observations)	Receiving the benefit (1) or not receiving the benefit (0).*	1-year intervals from one year (12 months) before injury to six years (72 months) after injury.

* The monthly observations were used as the basis for outcome assessment in 1-year intervals. To be registered with outcome/benefit, the persons had to be registered with benefits in at least 9 out of 12 months (or at least 75% of monthly registrations during the 1-year interval).

Abbreviation: SSB, Statistics Norway. NAV, The Norwegian Labour and Welfare Administration. NOK, Norwegian kroner. EUR, Euro

Table 2. Descriptive characteristics of the patients with spinal cord injury (N = 451) and matched controls (N=1791). N (%) or mean (sd).

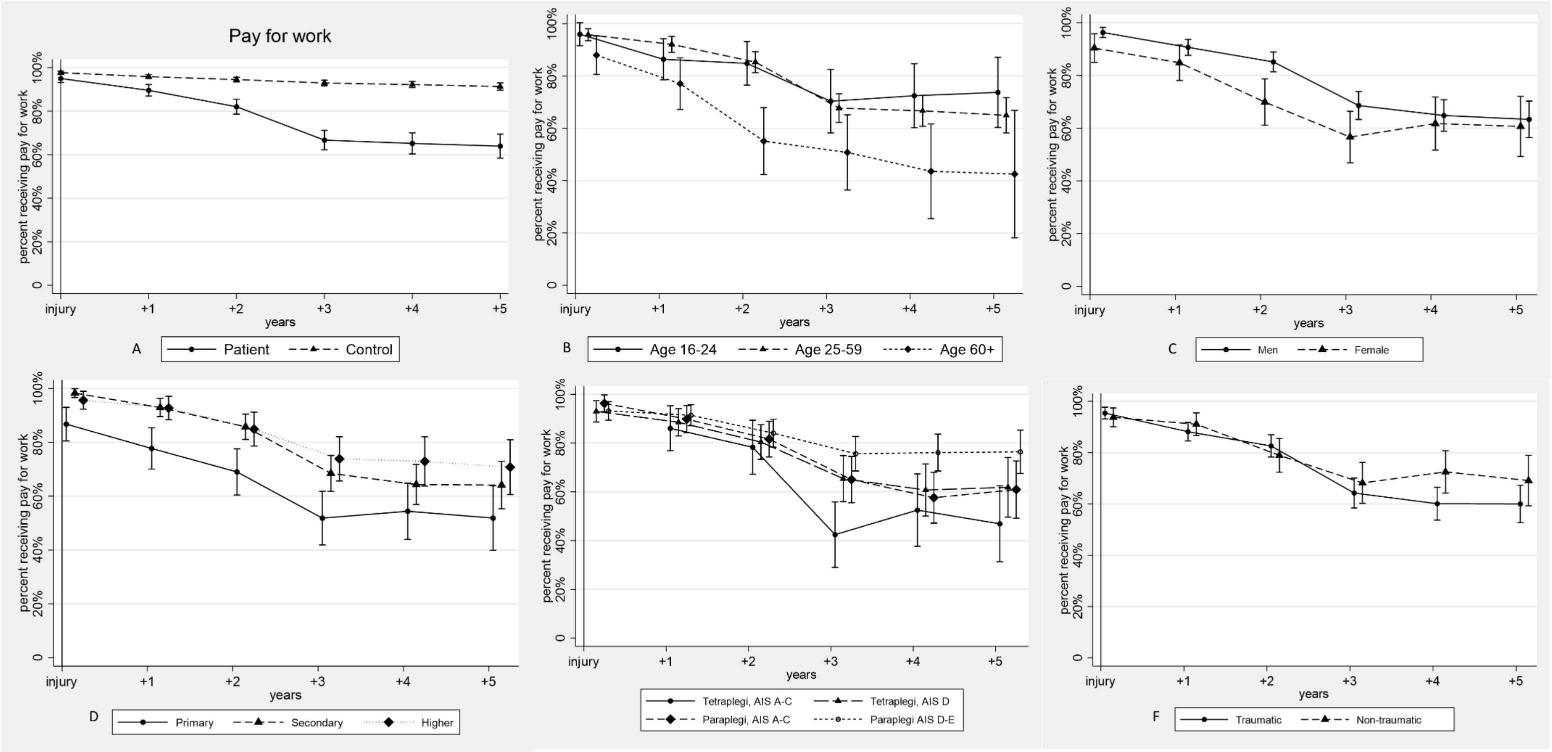
Characteristics	SCI population N=451	Control population N=1791
Mean age at injury, years (sd)	44 (15)	43 (14)
Age groups at injury N (%)		
16-29 years	102 (23)	422 (24)
30-39 years	68 (15)	281 (16)
40-49 years	90 (20)	375 (21)
50-59 years	111 (25)	431 (24)
60-66 years	80 (18)	282 (16)
Sex N (%)		
Male	343 (76)	1374 (77)
Female	108 (24)	417 (23)
Level of education year before injury N (%)		
Primary	117 (26)	395 (22)
Secondary	210 (47)	893 (50)
Higher	124 (27)	503 (28)
Ongoing education year before injury N (%)		
Yes	34 (8)	173 (10)
No	417 (92)	1618 (90)
Having an employer year before injury (at least 75% *)		
Yes	335 (74)	1373 (77)
No	116 (26)	418 (23)
Having an employer at least one moth in year before injury		
Yes	386 (86)	1545 (86)
No	65 (14)	246 (14)
Mean annual employment income before SCI in NOK (sd)	409.859 (316.792)	438.341 (387.143)
Mean annual employment income before SCI in EUR (sd)	42.540 (32.880)	45.496 (40.182)
Employment income groups N (%)		
0 – 299.999 NOK (0-31.137 EUR)	171 (38)	598 (34)
300.000 – 499.999 NOK (31.138-51.896 EUR)	130 (29)	589 (33)
500.000 – 999.999 NOK (51.897-103.791 EUR)	129 (29)	536 (30)
≥1.000.000 NOK (>103.792)	21 (5)	57 (3)
Receiving any sickness or disability benefit year before injury (at least 75%**)		
Yes	77 (17)	154 (9)
No	374 (83)	1637 (91)
Receiving any sickness or disability benefits in at least year before injury		
Yes	164 (36)	415 (23)
No	287 (64)	1376 (77)
SCI Characteristics		
Cause of injury N (%)		
Traumatic	301 (67)	
Non-traumatic	150 (33)	
Impairment groups (Level and AIS) N (%)		
Paraplegia, AIS D-E	159 (35)	
Tetraplegia, AIS D	113 (25)	
Paraplegia, AIS A-C	109 (24)	
Tetraplegia, AIS A-C	58 (13)	
Unknown or not applicable	12 (3)	
Year of injury N (%)		
2011	54 (12)	
2012	58 (13)	
2013	61 (14)	
2014	73 (16)	
2015	82 (18)	
2016	60 (13)	
2017	63 (14)	

* Being registered with employer in at least 9 out of 12 months (or at least 75% of monthly registrations during the 1-year interval)

** Being registered with sickness and disability benefits in at least 9 out of 12 months (or at least 75% of monthly registrations during the 1-year interval).

Abbreviation: NOK, Norwegian kroner. EUR, Euro. SCI, spinal cord injury. AIS, American Spinal Injury Association Impairment Scale.

Figure 1. Percentages receiving any amount of pay for work at each 1-year interval during follow-up *.
(Figures b, c, d, e, f for individuals with spinal cord injury only.)

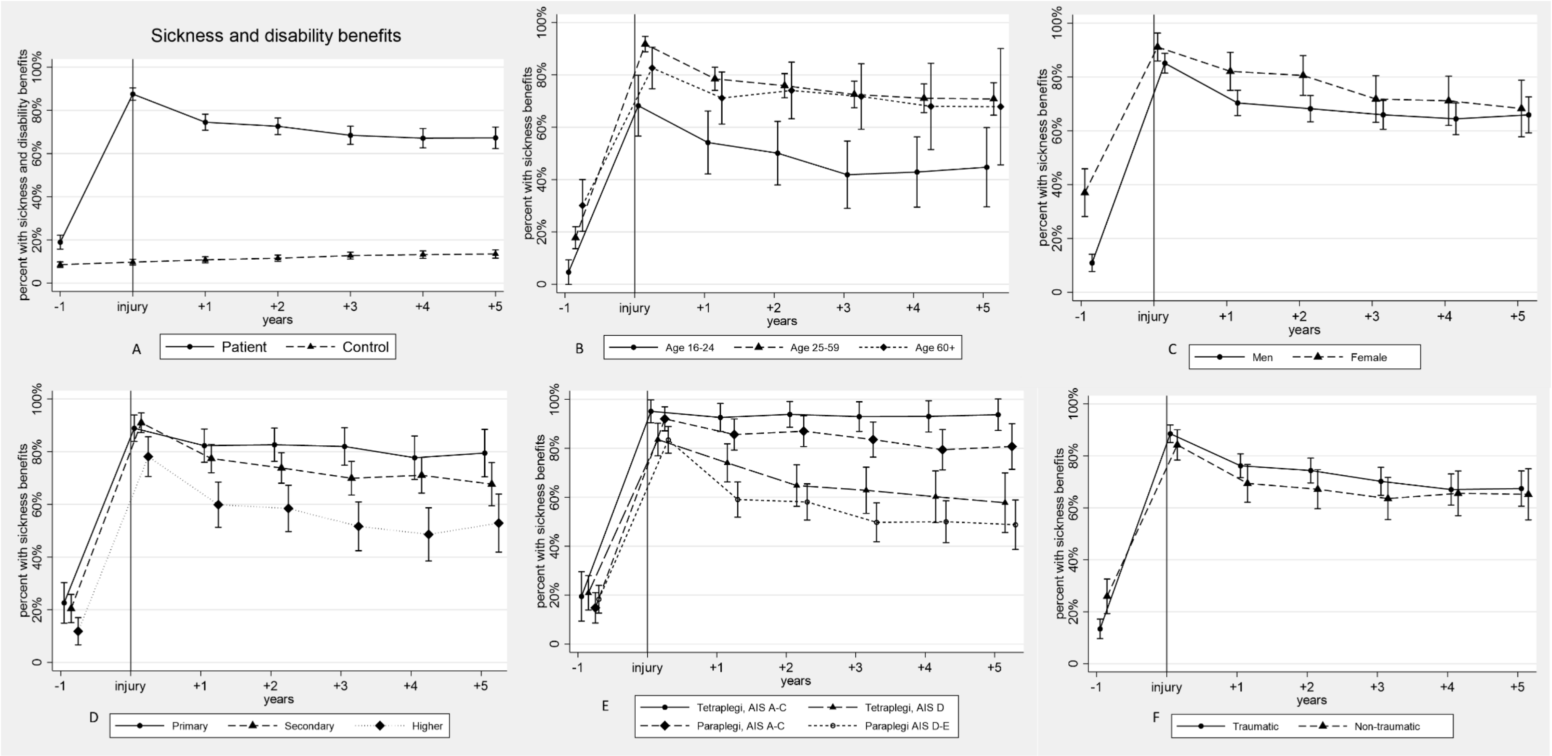


Footnote:

- Table displays results of the general estimation equations' (GEE) logistic regression models with "Receiving any amount of pay for work" as dependent variable.
  All models included adjustment for age, sex and educational level.
  Estimates from the analyses were used to calculate and graphically present the estimated percent receiving pay for work with 95% confidence intervals. The vertical line at injury indicates the time of spinal cord injury.

Abbreviation: AIS, American Spinal Injury Association Impairment Scale.
Primary, secondary, higher refers to the level of education. Traumatic refers traumatic spinal cord injury. Non-traumatic refers to non-traumatic spinal cord injury.

Figure 2. Percentages receiving sickness and disability benefits at each 1-year interval during follow-up *.
(Figures b, c, d, e, f for individuals with spinal cord injury only.)

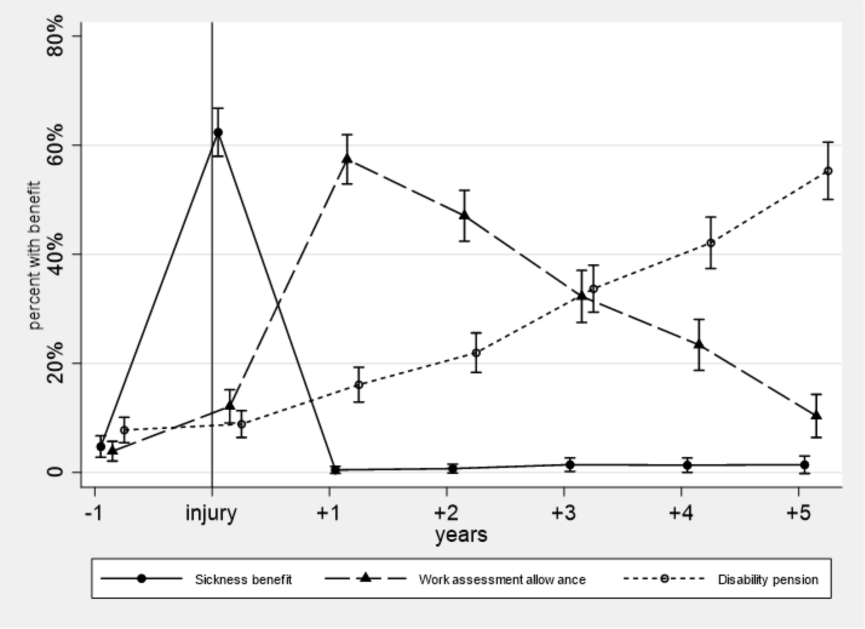


Footnote:

- Table displays results of the general estimation equations' (GEE) logistic regression models with "Receiving sickness and disability benefits" as dependent variable.
  All models included adjustment for age, sex and educational level.
  Estimates from the analyses were used to calculate and graphically present the estimated percent receiving pay for work with 95% confidence intervals. The vertical line at injury indicates the time of spinal cord injury.

Abbreviation: AIS, American Spinal Injury Association Impairment Scale.
Primary, secondary, higher refers to the level of education. Traumatic refers traumatic spinal cord injury. Non-traumatic refers to non-traumatic spinal cord injury.

Figure 3. Percentage of persons with spinal cord injury receiving different types of sickness and disability benefits over time during follow-up*.



*Footnote:
Table displays results of the general estimation equations' (GEE) logistic regression models with each of the sickness and disability benefits (sickness absence benefit, work assessment allowance and, disability pension) separately as dependent variable.
All models included adjustment for age, sex and educational level.
Estimates from the analyses were used to calculate and graphically present the estimated percent receiving each of the benefit with 95% confidence intervals. The vertical line at injury indicates the time of spinal cord injury.

Table 3. Comparisons of spinal cord injury (SCI) patients with controls within matched groups, reporting prevalence differences (in %-points) and odds ratios (OR) with 95% confidence interval (95%CI), for receiving 1) any amount of pay for work and 2)sickness and disability benefits.*

	Year before injury				**Year 1-3 after injury**				**Year 4-6 after injury**			
Outcomes	Prevalence difference	95% CI	OR	95% CI	Prevalence difference	95% CI	OR	95% CI	Prevalence difference	95% CI	OR	95% CI
Receiving any amount of pay for work												
SCI vs. controls					-25 %	[-30% - -21%]	0.3	[0.3-0.4]	-28 %	[-32% - -24%]	0.1	[0.1 - 0.1]
Sickness and disability benefits												
SCI vs. controls	21 %	[14% - 28%]	2.4	[1.7 - 3.4]	42 %	[37% - 47%]	129.2	[101.1 - 165.2]	36 %	[31% - 41%]	44.3	[34.9 - 56.3]

* Table displays within-group estimates from fixed effect logistic regression models.

Table 4. The impact of personal and injury characteristics on outcomes "Receiving any amount for pay for work" and "Receiving sickness and disability benefits".*

	Receiving pay for work						Receving sickness and disability benefits					
	Model A		Model B		Model C		Model A		Model B		Model C	
	OR	95% CI	OR	95% CI	OR	95% CI	OR	95% CI	OR	95% CI	OR	95% CI
Age group at injury												
16-29 years	ref		ref		ref		ref		ref		ref	
30-39 years	1.22	[0.69-2.15]	0.96	[0.53-1.73]	0.81	[0.43-1.51]	2.29	[1.30-4.01]	3.48	[1.96-6.19]	3.99	[2.23-7.13]
40-49 years	0.91	[0.54-1.54]	0.73	[0.42-1.28]	0.62	[0.34-1.13]	2.64	[1.55-4.48]	4.69	[2.67-8.24]	5.67	[3.11-10.31]
50-59 years	0.73	[0.45-1.20]	0.58	[0.34-0.98]	0.40	[0.22-0.73]	3.04	[1.81-5.09]	4.94	[2.83-8.60]	6.13	[3.35-11.20]
60-66 years	0.29	[0.16-0.51]	0.25	[0.14-0.45]	0.19	[0.10-0.35]	2.00	[1.14-3.52]	2.70	[1.49-4.89]	3.23	[1.75-5.95]
Sex												
Female	ref		ref		ref		ref		ref		ref	
Male	1.50	[1.02-2.20]	1.67	[1.11-2.52]	1.04	[0.68-1.61]	0.61	[0.40-0.93]	0.48	[0.31-0.74]	0.73	[0.47-1.14]
Level of education												
Primary education	ref		ref		ref		ref		ref		ref	
Secondary education	2.18	[1.45-3.27]	2.05	[1.33-3.15]	1.47	[0.95-2.30]	0.54	[0.34-0.86]	0.52	[0.33-0.84]	0.75	[0.46-1.21]
Higher education	2.75	[1.71-4.44]	2.67	[1.62-4.39]	1.42	[0.84-2.38]	0.28	[0.16-0.46]	0.26	[0.15-0.43]	0.39	[0.23-0.65]
SCI impairment group (level and AIS)												
Paraplegia AIS D-E			ref		ref				ref		ref	
Tetraplegia AIS D			0.52	[0.32-0.83]	0.65	[0.40-1.04]			1.74	[1.14-2.64]	1.54	[1.02-2.33]
Paraplegia AIS A-C			0.50	[0.31-0.80]	0.50	[0.31-0.81]			5.67	[3.40-9.45]	5.45	[3.35-8.87]
Tetraplegia AIS A-C			0.29	[0.16-0.52]	0.30	[0.17-0.54]			17.92	[7.96-40.32]	19.6	[9.04-42.53]
Cause of SCI injury												
Traumatic SCI			ref		ref				ref		ref	
Non-traumatic SCI			1.07	[0.71-1.62]	1.45	[0.94-2.22]			1.24	[0.83-1.84]	0.85	[0.58-1.26]
Year of injury												
Injury 2011-2014			ref		ref				ref		ref	
Injury 2015-2017			1.00	[0.69-1.45]	0.85	[0.58-1.25]			0.88	[0.62-1.27]	1.06	[0.74-1.51]
Work income **												
0-299,999 NOK					ref						ref	
300,000-499,999 NOK					2.27	[1.41-3.65]					1.16	[0.70-1.94]
500,000-999,999 NOK					3.52	[2.06-6.00]					0.42	[0.25-0.69]
1,000,000 or above					10.69	[2.76-41.47]					0.18	[0.07-0.45]
Sickness/disability benefit**												
No benefit					ref						ref	
Benefit					0.36	[0.24-0.53]					3.31	[2.19-5.00]
Having an employer **												
No					ref						ref	
Yes					1.38	[0.84-2.26]					0.86	[0.49-1.49]

* Table displays results of the logistic regression models.

Model A Adjusted for time, age groups, sex, level of education.

Model B Adjusted for time, age groups, sex, level of education, SCI impairment groups, cause of injury and year of injury

Model C Adjusted for time, age groups, sex, level of education, SCI impairment groups, cause of injury and year of injury, employment income before injury, employment status before injury and medical benefits before injury.

** During year before injury

Abbreviation: OR, Odds Ratio. CI Confidence Interval. NOK, Norwegian kroner. EUR, Euro. SCI, spinal cord injury. AIS, American Spinal Injury Association Impairment Scale.

Supplementary table 1. The number and percentage of participants in the spinal cord injury (SCI) sample and control sample who received (+) or did not receive (-) pay for work and/or sickness and disability benefits each year of follow-up.

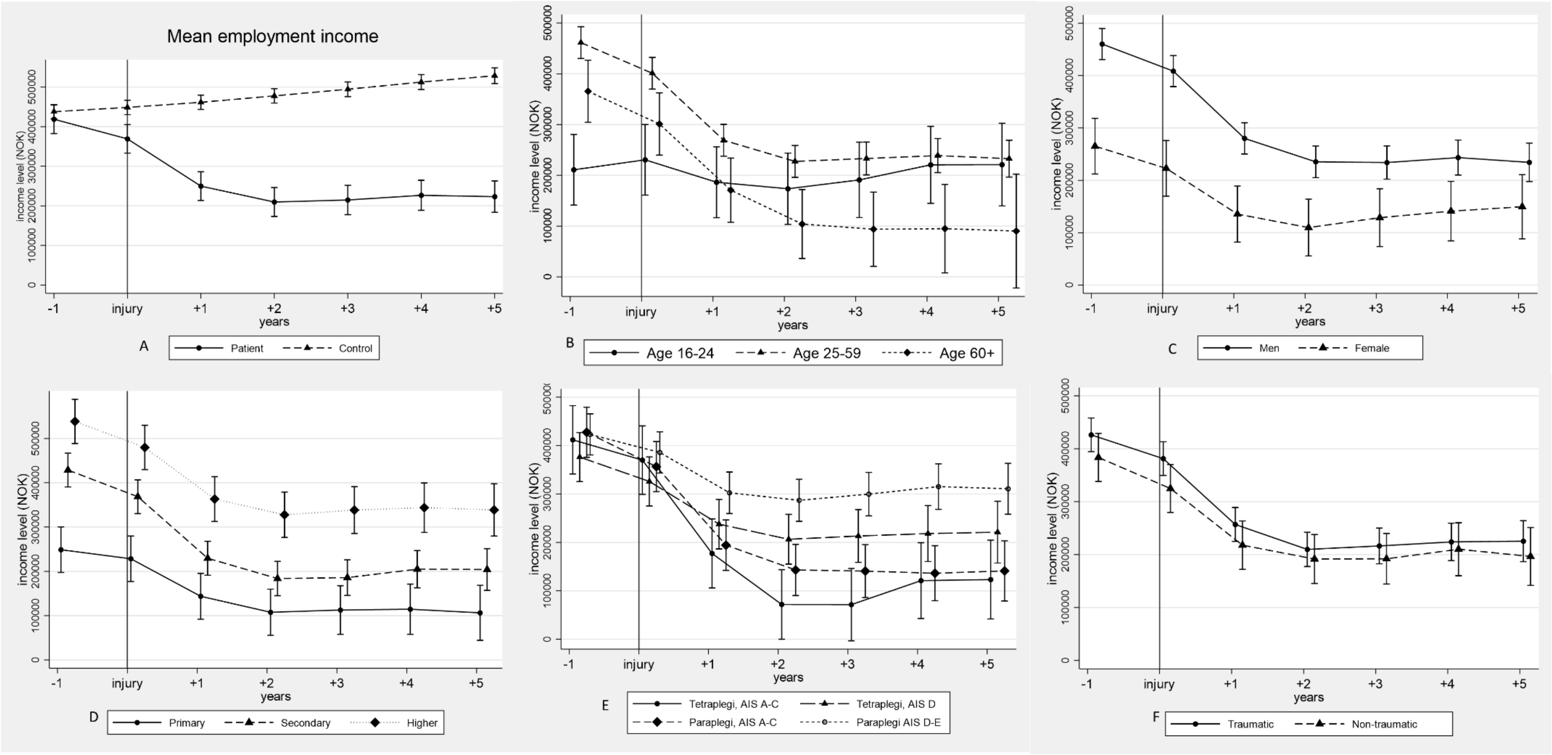
	Year of follow-up (before/after injury)						
	-1-0	0-1	1-2	2-3	3-4	4-5	5-6
N included SCI sample	451	451	436	414	345	283	202
Receiving any amount of pay for work + Sickness and disability benefits -	374 (83%)	55 (12%)	111 (25%)	115 (28%)	100 (29%)	84 (30%)	60 (30%)
Receiving any amount of pay for work + Sickness and disability benefits +	77 (17%)	372 (82%)	279 (64%)	225 (54%)	133 (39%)	105 (37%)	74 (37%)
Receiving any amount of pay for work - Sickness and disability benefits -		5 (1%)	5 (1%)	4 (1%)	7 (2%)	6 (2%)	5 (2%)
Receiving any amount of pay for work - Sickness and disability benefits +		19 (4%)	41 (9%)	70 (18%)	105 (30%)	88 (31%)	63 (32%)
N included control sample	1791	1790	1742	1700	1444	1192	841
Receiving any amount of pay for work + Sickness and disability benefits -	1637 (91%)	1588 (89%)	1522 (87%)	1467 (86%)	1226 (85%)	1010 (85%)	715 (85%)
Receiving any amount of pay for work + Sickness and disability benefits +	154 (9%)	157 (9%)	147 (8%)	143 (8%)	124 (9%)	99 (8%)	63 (8%)
Receiving any amount of pay for work - Sickness and disability benefits -		27 (2%)	34 (2%)	41 (2%)	40 (3%)	37 (3%)	23 (3%)
Receiving any amount of pay for work - Sickness and disability benefits +		18 (1%)	39 (2%)	49 (3%)	54 (4%)	49 (4%)	35 (4%)

Supplementary table 2. The distribution of participants in the spinal cord injury sample (SCI) and control sample in employment income groups each year of follow-up. N (%).

	Year of follow-up (before/after injury)						
	-1-0	0-1	1-2	2-3	3-4	4-5	5-6
N included SCI sample	451	451	436	414	345	283	202
0 or less NOK	0 (0%)	24 (5%)	46 (11%)	74 (18%)	112 (32%)	94 (33%)	68 (34%)
0-299.999 NOK	171 (38%)	172 (38%)	263 (60%)	226 (55%)	135 (39%)	112 (40%)	77 (38%)
300.000 -499.999 NOK	130 (29%)	141 (31%)	54 (12%)	52 (13%)	36 (10%)	27 (10%)	22 (11%)
500.000-999.999 NOK	129 (29%)	96 (21%)	60 (14%)	48 (12%)	54 (16%)	46 (16%)	34 (17%)
More than 1.000.000 NOK	21 (5%)	18 (4%)	13 (3%)	14 (3%)	8 (2%)	4 (1%)	1 (1%)
N included control sample	1780	1777	1732	1687	1432	1184	837
0 or less NOK	0 (0%)	45 (3%)	73 (4%)	90 (5%)	94 (7%)	83 (7%)	58 (7%)
0-299.999 NOK	598 (34%)	552 (31%)	488 (28%)	410 (24%)	304 (21%)	229 (19%)	153 (18%)
300.000 -499.999 NOK	589 (33%)	550 (31%)	508 (29%)	491 (29%)	392 (27%)	317 (27%)	213 (25%)
500.000-999.999 NOK	536 (30%)	566 (32%)	589 (34%)	619 (37%)	566 (40%)	489 (41%)	364 (43%)
More than 1.000.000 NOK	57 (3%)	64 (4%)	74 (4%)	77 (5%)	76 (5%)	66 (6%)	49 (6%)

Abbreviation: NOK, Norwegian kroner.

Supplementary figure 1. Mean level of employment income at each 1-year interval during follow-up*. (Figures b, c, d, e, f for individuals with spinal cord injury only.)

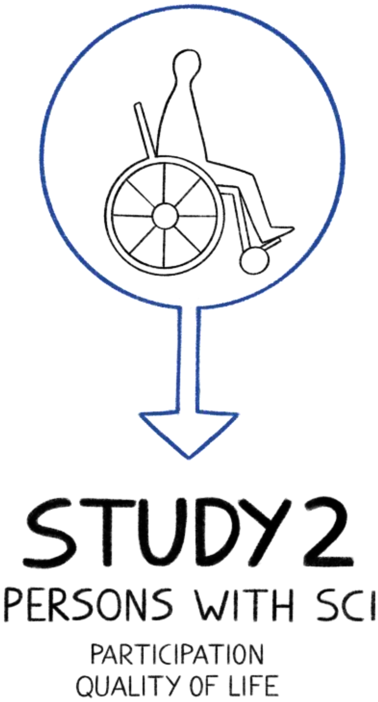


Footnote:

- Table displays results of the general estimation equations' (GEE) linear regression models with "Mean employment income" as dependent variable.
  All models included adjustment for age, sex and educational level.
  Estimates from the analyses were used to calculate and graphically present the estimated percent for level of income with 95% confidence intervals. The vertical line at injury indicates the time of spinal cord injury.

Abbreviation: AIS, American Spinal Injury Association Impairment Scale.
Primary, secondary, higher refers to the level of education. Traumatic refers to traumatic cause of spinal cord injury. Non-traumatic refers to non-traumatic cause of spinal cord injury.

Paper II



J Rehabil Med 2021; 53: jrm00217

ORIGINAL REPORT

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

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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

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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).

Foundation of Rehabilitation Information

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 χ^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/

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

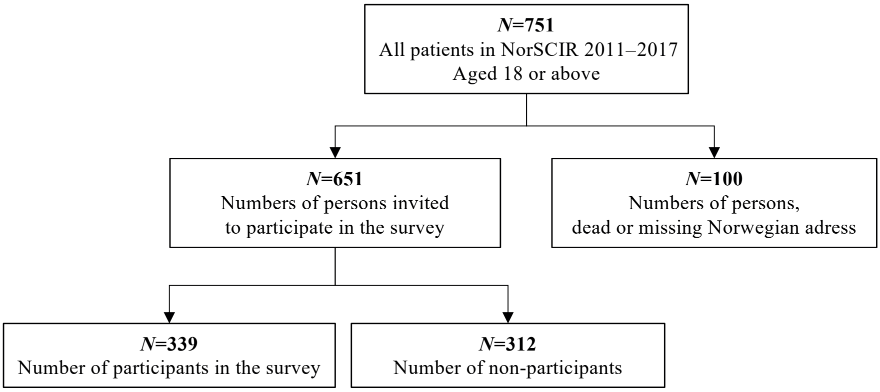

Fig. 1. Flow-chart of study participants.

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 χ^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 ($n = 329$)

Variables (Quartile, Score range)	Life satisfaction (WHOQoL-5) Mean (95%CI) Unadjusted model	Life satisfaction (WHOQoL-5) Mean (95%CI) Adjusted model[a]	Mental health (MHI-5) Mean (95%CI) Unadjusted model	Mental health (MHI-5) Mean (95%CI) 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.

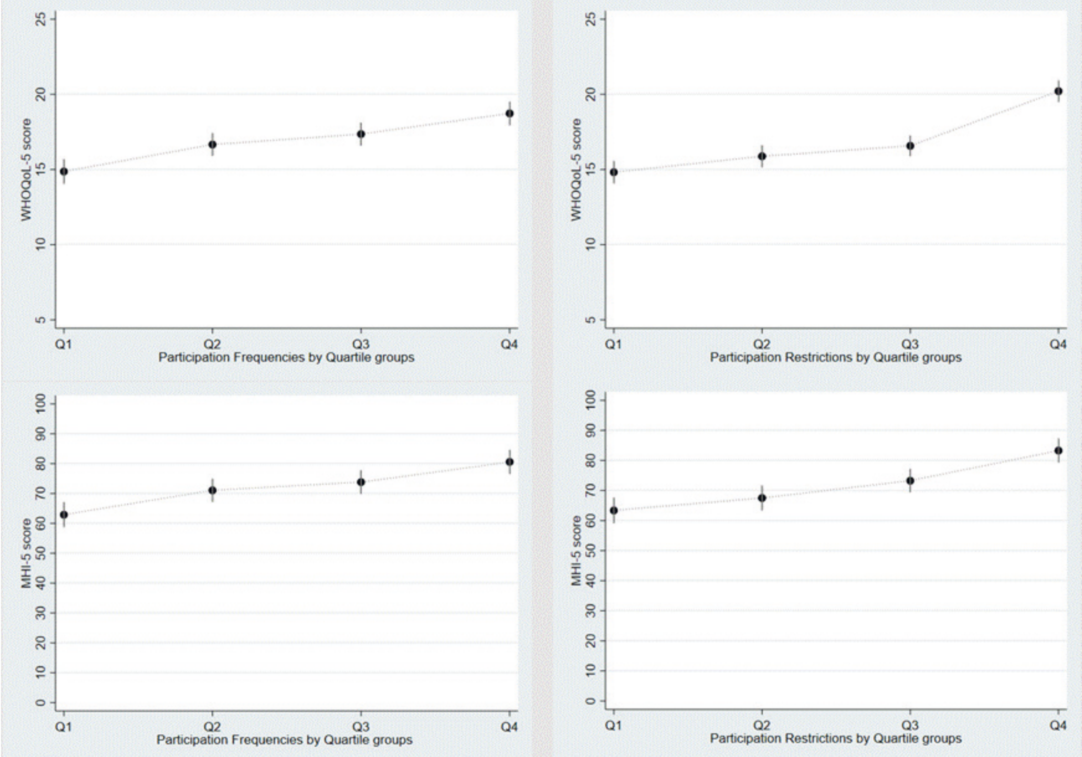

Fig. 2. Adjusted association between participation (frequencies and restrictions) and quality of life (life satisfaction and mental health).

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.

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Supplementary material to article by A. Halvorsen et al. "Participation and quality of life in persons living with spinal cord injury in norway"

Table SI. Proportion of participants answering each of the answering categories on the single items in the USER-P Frequency score

Question	*n*	Answering options					
Vocational activities score		Not at all, %	1–8 hours per week, %	9–16 hours per week, %	17–24 hours per week, %	25–35 hours per week, %	36 hours or more per week, %
Paid work	326	69.3	6.1	4.0	5.8	1.5	13.2
Unpaid work	327	61.8	27.5	7.0	2.5	0.6	0.6
Education	337	92.6	3.0	0.9	0.3	2.7	0.6
Household duties	338	13.9	44.1	26.3	8.9	5.6	1.2
Leisure and social activities score		Never, %	1–2 times last four weeks, %	3–5 timer last four weeks, %	6–10 timer last four weeks, %	11–18 timer last four weeks, %	19 timer or more last four weeks, %
Sports or physical exercise	336	17.9	11.6	16.7	24.4	16.1	13.4
Going out	332	26.2	35.8	23.5	11.5	2.1	0.9
Daytrips and other outdoor activities	333	15.0	23.4	30.3	17.7	8.4	5.1
Leisure activities at home	333	17.1	17.7	10.8	17.4	13.2	23.7
Going to visit family or friends	330	16.4	28.8	31.2	16.7	6.4	0.6
Family or friends coming to visit at your home	339	9.1	27.4	35.4	19.8	5.9	2.4
Contacting others by telephone/computer	339	2.4	7.1	15.3	22.7	12.7	39.8

USER-P Frequency: Frequency scale of Utrecht Scale for Evaluation of Rehabilitation-Participation.

Supplementary material to article by A. Halvorsen et al. "Participation and quality of life in persons living with spinal cord injury in norway"

Table SII. Proportion of the participants answering each of the answering categories on the single items in the USER-P Restrictions score

Questions	*n*	Answering options				
Restrictions score		NA, %	Not possible, %	With assistance, %	With difficulty, %	Without difficulty, %
Paid work, unpaid work or education	335	37.0	18.2	4.8	26.3	13.7
Household duties	332	8.1	10.5	15.1	47.9	18.4
Outdoor mobility	331	3.3	6.7	15.4	40.2	34.4
Sports or other physical exercise	330	7.3	11.5	12.7	49.1	19.4
Going out	332	8.4	2.7	20.8	35.8	32.2
Daytrips and other outdoor activities	336	5.7	3.6	22.6	42.3	25.9
Leisure activities at home	337	10.7	3.0	5.3	20.5	60.5
Relationship with your partner	326	30.1	14.4	5.2	20.9	29.5
Going to visit family or friends	337	3.6	3.0	23.2	33.2	37.1
Family or friends coming to visit at your home	326	3.4	0.3	8.3	25.2	62.9
Contacting others by telephone/computer	327	2.8	0.3	3.7	8.9	84.4

USER-P Restrictions: Restriction scale of Utrecht Scale for Evaluation of Rehabilitation-Participation; NA: Not applicable.

Supplementary material to article by A. Halvorsen et al. "Participation and quality of life in persons living with spinal cord injury in norway"

Table SIII. Proportion of the participants answering each of the answering categories on the single items in the WHOQoL-5

		Answering options				
Question	*n*	Very poor, %	Poor, %	Neither good nor poor, %	Good, %	Very good, %
How would you rate your QoL?	333	2.4	15.3	33.3	39.9	9.0
		Very dissatisfied, %	Dissatisfied, %	Neither satisfied/nor dissatisfied, %	Satisfied, %	Very satisfied, %
Satisfaction with health	331	10.0	32.0	25.1	29.6	3.3
Satisfaction with daily activities	333	8.1	28.2	22.5	34.2	6.9
Satisfaction with personal relationships	334	1.5	7.8	17.7	54.2	18.9
Satisfaction with living conditions	332	3.0	8.1	13.0	49.7	26.2

WHOQoL-5: World Health Organization Quality of life assessment; QoL: Quality of Life.

Supplementary material to article by A. Halvorsen et al. "Participation and quality of life in persons living with spinal cord injury in norway"

Table SIV. Proportion of the participants answering each of the answering categories on the single items in the MHI-5

Question	*n*	All of the time, last four weeks, %	Almost all of the time, last four weeks, %	Some of the time, last four weeks, %	A little of the time, last four weeks, %	None of the time, last four weeks, %
Nervous person	339	1.2	2.7	10.0	30.7	55.5
Felt down	339	0.6	3.2	9.4	24.2	62.5
Calm and peaceful	339	10.6	43.7	22.7	16.5	6.5
Downhearted and blue	330	0.9	7.3	17.9	36.1	37.9
Happy person	331	6.3	33.2	36.9	20.2	3.3

MHI-5: Mental Health subscale of the Medical Outcomes Study Short Form Health Survey.

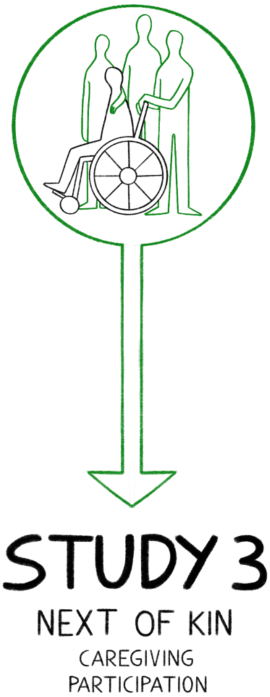
Supplementary material to article by A. Halvorsen et al. "Participation and quality of life in persons living with spinal cord injury in norway"

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

		USER-P freq		USER-P restr		WHO QoL-5		MHI-5	
		Range 0–100		Range 0–100		Range 5–25		Range 0–100	
Variable	*n* (%)	Mean (95% CI)	*p*-value	Mean (95% CI)	*p*-value	Mean (95% CI)	*p*-value	Mean (95% CI)	*p*-value
Mean score (SD)	339 (100)	30.7 (11.9)		70.3 (20.5)		16.9 (3.7)		71.9 (19.5)	
Demographic variables									
Age-groups at time of survey									
18–29 years	29 (9)	37.0 (32.9–41.1)	Ref	80.0 (73.1–87.0)	Ref	17.5 (16.1–18.8)	Ref	66.6 (59.4–73.9)	Ref
30–59 years	130 (38)	33.6 (31.7–35.6)	0.151	73.0 (69.7–76.3)	0.073	16.4 (15.7–17.0)	0.171	67.4 (64.0–70.8)	0.857
60 years	180 (53)	27.7 (26.1–29.4)	< 0.001[c]	66.9 (64.1–69.7)	0.001[c]	17.2 (16.7–17.8)	0.772	76.5 (73.6–79.4)	0.014[c]
Sex									
Male	243 (72)	30.8 (29.3–32.2)	Ref	71.8 (69.4–74.1)	Ref	16.7 (16.2–17.2)	Ref	72.9 (70.4–75.3)	Ref
Female	96 (28)	31.1 (28.8–33.4)	0.815	66.9 (63.0–70.8)	0.039[c]	17.5 (16.8–18.3)	0.069	70.7 (66.1–74.1)	0.257
Level of education									
Primary	50 (15)	24.0 (20.8–27.1)	ref	61.7 (56.4–67.0)	Ref	15.4 (14.3–16.5)	Ref	69.7 (64.3–75.2)	Ref
Secondary	151 (45)	29.7 (27.9–31.5)	0.002[c]	68.3 65.3–71.2)	0.036[c]	16.9 (16.3–17.5)	0.015[c]	72.2 (69.1–75.3)	0.440
Higher	132 (40)	34.8 (32.9–36.7)	< 0.001[c]	76.1 (72.9–79.4)	< 0.001[c]	17.5 (16.8–18.1)	0.001[c]	72.9 (69.6–76.2)	0.328
Spinal cord injury characteristics									
Time since discharge									
4 years or less	155 (46)	30.9 (29.2–32.7)	Ref	68.5 (65.6–71.4)	Ref	17.1 (16.4–17.5)	Ref	72.5 (69.5–75.5)	Ref
More than 4 years.	184 (54)	30.8 (29.1–32.4)	0.902	72.1 (69.3–74.8)	0.085	16.9 (16.3–17.5)	0.892	71.8 (68.9–74.6)	0.731
Cause of injury									
Traumatic	203 (60)	31.2 (29.7–32.8)	Ref	70.7 (68.1–73.4)	Ref	17.0 (16.5–17.5)	Ref	71.0 (68.3–73.8)	Ref
Non-traumatic	136 (40)	30.2 (28.2–32.2)	0.452	69.9 (66.6–73.2)	0.719	16.8 (16.2–17.5)	0.218	73.8 (70.3–77.2)	0.238
Impairment groups (level and AIS)									
Tetraplegia A,B,C	34 (10)	28.0 (24.1–31.8)	Ref	51.5 (45.2–57.9)	Ref	16.6 (15.3–17.8)	Ref	73.5 (66.9–80.1)	Ref
Tetraplegia D,E	102 (30)	30.5 (28.3–32.6)	0.266	72.5 (68.8–76.2)	< 0.001[c]	16.5 (15.8–17.3)	0.848	71.9 (68.0–75.7)	0.462
Paraplegia A,B,C	76 (23)	31.6 (29.1–34.0)	0.125	70.8 (66.6–75.1)	< 0.001[c]	17.4 (16.6–18.3)	0.096	72.1 (67.7–76.5)	0.956
Paraplegia D,E	123 (37)	31.5 (29.5–33.6)	0.118	73.7 (70.3–77.1)	< 0.001[c]	17.0 (16.4–17.7)	0.205	71.0 (67.5–74.5)	0.622
Social variables									
Main daily activity									
Currently working	75 (23)	37.3 (34.6–40.1)	Ref	77.0 (72.2–81.7)	Ref	18.6 (17.7–19.6)	Ref	77.3 (72.3–82.2)	Ref
Retirement age	113 (34)	28.1 (25.6–30.5)	< 0.001[c]	67.9 (63.6–72.2)	0.013[c]	16.5 (15.7–17.4)	0.003[c]	71.4 (67.0–75.9)	0.128
Social welfare recipient	120 (36)	28.6 (26.6–30.5)	< 0.001[c]	67.5 (64.1–70.9)	0.001[c]	16.3 (15.6–17.0)	< 0.001[c]	69.9 (66.3–73.5)	0.016[c]
Students	11 (3)	41.1 (34.4–47.8)	0.297	83.9 (72.1–95.7)	0.269	17.3 (15.0–19.6)	0.277	75.4 (63.0–87.7)	0.771
Other (homemaker, jobseeker)	14 (4)	28.2 (22.6–33.9)	0.003[c]	69.8 (59.9–79.6)	0.183	16.1 (14.2–18.1)	0.018[c]	66.3 (56.0–76.6)	0.054
Living situation									
Alone	104 (31)	30.5 (28.3–32.7)	Ref	70.3 (66.6–73.9)	Ref	16.3 (15.6–17.1)	Ref	66.4 (62.7–70.1)	Ref
Together	227 (69)	31.0 (29.5–32.4)	0.729	70.3 (67.9–72.7)	0.989	17.2 (16.7–17.6)	0.064	74.6 (72.1–77.0)	< 0.001[c]
Family income (Norwegian kroner per year)									
Below 250.000	29 (9)	25.0 (20.8–29.3)	Ref	66.3 (59.3–73.4)	Ref	15.8 (14.4–17.2)	Ref	58.9 (51.6–66.2)	Ref
250.000 to 500000	107 (35)	29.9 (27.8–32.0)	0.042[c]	68.7 (65.3–72.2)	0.544	16.5 (15.7–17.2)	0.424	70.4 (66.8–74.0)	0.005[c]
500.000 to 750.000	76 (25)	30.6 (28.2–33.0)	0.028[c]	71.9 (67.9–75.9)	0.182	16.7 (15.8–17.5)	0.308	73.3 (69.1–77.4)	0.001[c]
750.000 to 1 million	52 (17)	33.2 (30.2–36.2)	0.003[c]	73.8 (68.9–78.7)	0.093	17.1 (16.1–18.1)	0.160	72.3 (67.2–77.4)	0.004[c]
Above 1 million	44 (14)	35.0 (31.7–38.3)	< 0.001[c]	76.7 (71.3–82.2)	0.025[c]	19.2 (18.1–20.3)	< 0.001[c]	82.8 (77.2–88.4)	< 0.001[c]

[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] *n* vary from 339 to 295 for each variable due to missing or preferring not to answer. [c] *p*-value <0.05 from linear regression. 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.

Paper III



STUDY 3

NEXT OF KIN

CAREGIVING
PARTICIPATION
QUALITY OF LIFE

J Rehabil Med 2022; 54: jrm00278

ORIGINAL REPORT

CARIGIVING, PARTICIPATION, AND QUALITY OF LIFE OF CLOSEST NEXT OF KIN OF PERSONS LIVING WITH SPINAL CORD INJURY IN NORWAY

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Objectives: **To investigate how next of kin of persons with spinal cord injury (SCI) experience various life areas in terms of caregiving, participation, and quality of life, and the impact of personal characteristics of next of kin and SCI characteristics.**

Design: **Survey of next of kin linked to data on persons with SCI in the Norwegian SCI Registry.**

Participants: **A total of 73 next of kin identified by persons with SCI.**

Methods: **Outcome measures were caregiving (4 measures), participation (1 measure), and quality of life (2 measures).**

Results: **Participants (73% partners, 73% female, mean age 56.4 years) gave various support to the person with SCI and considered it important to care and were happy to do so. Three-quarters of participants reported good mental health and life satisfaction, while one-quarter reported high levels of caregiver strain, especially related to emotional adjustments. Higher levels of caregiver strain were reported by participants of working age (< 67 years), and by those with middle level education.**

Conclusion: **The majority of next of kin of persons living with SCI in Norway are doing well in most life areas. Caregiver strain may be reduced by strengthening the ability of next of kin to cope with emotional challenges.**

Key words: spinal cord injury; caregiver; caregiver burden; participation; quality of life; Norway.

Accepted Feb 15, 2022; Epub ahead of print Mar 9, 2022

J Rehabil Med 2022; 54: jrm00278

DOI: 10.2340/jrm.v54.2162

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LAY ABSTRACT

A spinal cord injury (SCI) often drastically disrupts the lives of both the individuals with SCI and the people surrounding them, such as family members. Caregiving for a loved one with SCI involves both physical and emotional investment. A survey was carried out of the caregivers of 73 persons living with SCI in Norway to assess their life situation. The study found that the majority of caregivers of persons living with SCI in Norway are doing well in most life areas. Three out of 4 caregivers reported good mental health and life satisfaction. All participants considered it important to care and most were happy to do so. Nevertheless, one-quarter reported high levels of strain, especially related to emotional adjustments. Most at risk for caregiver strain were participants of working age and those with secondary education. Caregiver strain may be reduced by strengthening the ability of the caregiver to cope with emotional challenges.

Spinal cord injury (SCI) often drastically disrupts the lives of both the individuals with SCI and the people surrounding them. Many next of kin (close relatives, spouses, etc.) provide extensive support to persons with SCI (1, 2). This support is often necessary for persons with SCI to continue living at home and to maintain their well-being (3). Previous studies have reported that between 25% and 50% of partners of persons with SCI experience high levels of caregiver burden (4, 5).

The level of caregiver burden can be influenced by caregiver characteristics, such as age, sex, level of education, occupation status, and the type of relationship between caregiver and care recipient (2, 4, 6). In addition, the personal and injury characteristics of the person with SCI receiving support impacts the support provided and the perceived caregiver burden (2). However, the majority of previous studies of next of kin are based on samples that are not representative of the population of next of kin of persons with SCI and on self-reported data on injury characteristics provided by the caregiver (2). Therefore, studies using clinical register data, which may be available from SCI quality registers, are needed to improve the trustworthiness of the data.

The demands placed on the next of kin of persons with SCI can affect various life areas. Next of kin can experience strained relationships, less control over life, increased stress, and financial difficulties (7–9). There are only a few studies on objective burden of support (1, 4, 10), caregiver participation (11), and positive caregiver experiences (12). These studies show that next of kin provide support in many different types of activities, and that the next of kin of persons with a more severe disability more often provide practical everyday support.

However, currently, most studies in this field are limited to measuring the impact of SCI on 1 or 2 life areas of next of kin, and the broader picture is thus lacking. The results of such a study with a broader approach can be used to identify groups of next of kin who are at risk.

Although Norway has a relatively good health and social system for persons with SCI (13) and the National Norwegian SCI registry (NorSCIR) provides a good overview of the SCI population (www.norscir.no), to date, no information about the next of kin of persons with SCI in Norway exists. This study utilized NorSCIR to recruit a representative sample with good-quality clinical data on SCI characteristics in order to study the life situation of closest next of kin of persons living with SCI in Norway.

This study aimed to describe the next of kin of persons with SCI in Norway and to identify how the personal characteristics of next of kin and the injury characteristics of the related person with SCI, influence different life areas of next of kin; caregiving (objective and subjective burden of care, and positive experiences), participation, and quality of life (QoL) (life satisfaction, and mental health).

METHODS

Study design

The study includes survey data from next of kin linked to data on persons with SCI in NorSCIR. It is part of a research project concerning participation and QoL among persons registered in NorSCIR between 2011 and 2017 and their next of kin.

Participants

During 2019, all persons in NorSCIR were invited to participate in the "Survey among persons with SCI". Of the 651 invited persons with SCI, 339 participated (52%). All participants were asked to provide contact information for their designated next of kin so that the next of kin could be invited to participate in the "Next of kin survey". Next of kin was defined in the questionnaire as "A person who provides unpaid support, or the one who is closest to you. Usually it is a partner or other close relative, such as parent, child or sibling".

Procedures

A digital invitation was sent to all 92 designated next of kin. Those not registered with a digital mailbox or not answering the digital questionnaire were invited by post. Up to 2 reminders were sent to non-responders. To create awareness among those who were invited, general information about the study was published on the Facebook page and in the magazine of members of the Norwegian SCI consumer organization "LARS".

Ethical approval for the study was obtained from the Regional Committee for Medical and Health Research Ethics in Central Norway (2018/294/REK midt).

Measures

Sociodemographic characteristics of next of kin. This information included sex, age, level of education (categorized as primary, middle and higher (college/university) level of education), personal income, vocational status (categorized as currently working or student, retirement pension, social welfare recipient, or other (homemaker, jobseeker)) status and type of relation to the person with SCI. Age was categorized into 3 groups (<55, 55–67 and >67 years), as the retirement age in Norway is 67 years. Personal income was categorized into 2 groups (below and above 500,000 Norwegian kroner per year (approximately 49,500 EUR)).

Spinal cord injury characteristics. Injury characteristics were obtained from NorSCIR, which contains data registered by clinicians using the definitions from the International SCI Core Data Set version 1.1 (14). Study variables included dates of discharge from rehabilitation care, cause of injury and neurological status at discharge from rehabilitation hospital. Causes were categorized as traumatic or non-traumatic. The International Standards for Neurological Classification of Spinal Cord Injury (ISNCSCI) was used to document neurological level of injury and the severity of SCI, as described by the American Spinal Injury Association (ASIA) Impairment Scale (AIS) (15). These characteristics were coded in 4 categories: Tetraplegia (C1–C8) AIS A, B or C; Tetraplegia (C1–C8) AIS D; Paraplegia (T1–S5) AIS A, B or C; Paraplegia (T1–S5) AIS D. None was registered with AIS E.

Outcome measures

Outcome measures were: caregiving (objective burden, subjective burden, and positive caregiver experience), participation, and quality of life, as described below.

Objective burden of care. The objective burden of care for next of kin was measured by a measure of types and frequency of support (1, 4). The measure includes 3 categories of support: activities of daily living (ADL) support (13 items), other practical support (9 items) and emotional support (2 items). Response categories are: never (1), sometimes (2), often (3) and always (4). The total score is the mean of the item scores (range 1–4). Translation of the questionnaire from Dutch to Norwegian was performed according to the guidelines from the World Health Organization (WHO) for the process of translation and adaptation of instruments (16).

Subjective burden of care. It has been recommended to measure subjective burden of care using 2 instruments that complement each other (17); 1 instrument that measures different dimensions of burden, and 1 instrument that measures the caregiver's overall assessment of burden.

The Caregiver Strain Index (CSI) (18) evaluates strain related to care provision, by asking the responder to think of the person he/she is giving care to and to indicate if the following 13 dimensions apply to him/her (yes, no, not applicable), such as sleep disturbances, inconvenience, physical strain, and emotional adjustment. The total CSI score is calculated by summing up the "yes" responses, ranging from 0 to 13. Positive responses to 7 or more items on the index indicate a greater level of strain (4, 18). The CSI has been validated (18, 19) and the available Norwegian version was used (20).

The self-rated burden (SRB) (21) is a single question; "How demanding is it for you to provide care at the moment?". It is scored on an 11-point scale, from 0 "not demanding at all" to 10 "much too demanding". SRB is feasible and considered to be at least as valid as other measures of burden (21). It was translated into Norwegian for this study.

Positive caregiver experiences. To describe the positive experiences of caregiving, the current study used the 5 positive items that were added to the CSI in the Caregiver Strain Index Expanded (22). Positive experiences related to care provision are assessed by asking the responder to think of the person he/she is giving care to and to indicate if the subsequent 5 dimensions apply to him/her (yes, no, not applicable): such as I am happy to care, and I handle the care fine.

Participation. The Utrecht Scale for Evaluation of Rehabilitation-Participation (USER-Participation) Frequency subscale was used to measure the frequency of, and time spent on participation in different activities (23). The USER-Participation showed good validity (23), can also be used in people without physical disabilities, such as next of kin, and the 3 scales can be used separately (24). The English version of the USER-Participation was translated into Norwegian using the same guidelines (16). The frequency scale consists of 2 parts. Part A comprises 4 items on the number of hours spent per week on vocational activities, with answering options ranging from not at all (scored 0), to 36 h or more (scored 5). Part B comprises 7 items on leisure and social activities frequency in the last 4 weeks, with answering options ranging from never (scored 0) up to 19 times or more (scored 5). The sum score based on all applicable items is converted to a 0–100 scale, with higher scores indicating higher levels of participation.

Quality of life. QoL was measured, using 2 constructs, as described in the literature (25–27); life satisfaction and mental health. Life satisfaction was measured with a selection of 5 items from the World Health Organization Quality of life assesment-BREF (WHOQOL-BREF) assessment covering satisfaction with overall QoL, health, daily activities, relationships, and living conditions (World Health Organization Quality of life assessment; WHOQOL-5) (28). Response options range from very poor/very dissatisfied (scored 1) to very good/very satisfied (scored 5) for each item, yielding a total score between 5 (very poor/dissatisfied) and 25 (very good/satisfied).

Mental health was measured with the Mental Health subscale of the Medical Outcomes Study Short Form Health Survey (MHI-5) (29). The MHI-5 consists of 5 items on emotional status concerning nervousness, sadness, peacefulness, depressed mood, and happiness. Respondents rated the frequency of each item during the previous 4 weeks on a 5-point scale. The score is converted to a total score between 0 (lowest mental health) and 100 (highest mental health).

Statistical analysis

Descriptive statistics were used to assess the personal characteristics of the participating next of kin, and injury characteristics of their relation with SCI. Characteristics of participants in the "Survey among persons with SCI" who did or did not have next of kin participating in the current study were compared to assess the representativeness of the next of kin sample.

In separate analyses, with objective burden, participation and each dimension of subjective burden (CSI and SRB) and QoL (WHO QoL5 and MHI-5) as dependent variables, the associations with characteristics of next of kin and the injury characteristics of their relation with SCI as independent variables were assessed. Multivariable linear regression analyses, adjusted for sex and age as a continuous variable, were carried out. Stata® version 16.0 (StataCorp, College Station, TX, USA) was used for all statistical analyses.

RESULTS

Of the 339 persons with SCI who participated in the “Survey among persons with SCI”, 92 persons (27%) provided contact information of their designated next of kin who were invited to participate in this study. Of the 92 persons invited to participate in the “Next of kin survey”, 73 participated (79%) (Fig. 1).

Of the related persons with SCI, 59% had a traumatic SCI, 34% had tetraplegia AIS D and the mean time since discharge from primary rehabilitation was 4.2 years (standard deviation (SD) 1.8, range 1–8 years), at the time of the study (Table I). No significant differences in the characteristics of the persons with SCI were observed between those with vs without related to next of kin participating in this study (Table I).

Descriptive characteristics of the next of kin are shown in Table II. Mean age at the time of the survey was 56 years (median 59 years, range 20–79 years), 73% were female, and 55% had a high level of education (college/university). The majority were a spouse or partner of the person with SCI (73%), and 72% lived together (Table II).

Caregiving – objective burden of care

The mean support score for all respondents was 1.6 (SD 0.5) on a 1–4 scale (Table III). Next of kin of persons with tetraplegia AIS A–C reported providing more support than next of kin of persons with less severe disability.

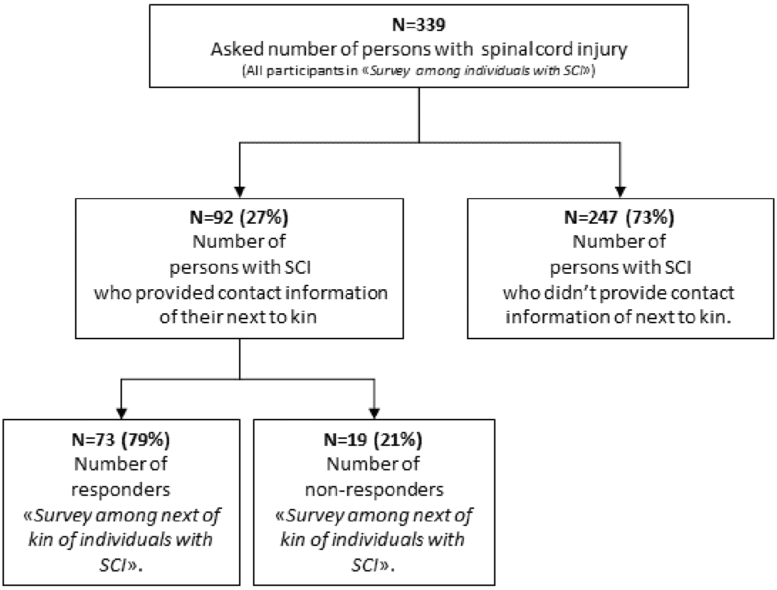
The types and frequencies of support given by next of kin are described in Table IV. Regarding support for ADL, most support was given in preparing meals (44%). This was followed by providing outdoor transportation and various “helping hands” throughout the day. Generally, less support was reported regarding “other practical support”, where most support was given when visiting a doctor (16%). Emotional support in terms of comforting and learning to live with SCI was given often or always by more than one-quarter of next of kin.

Caregiving – subjective burden of care

The mean overall SRB score was 3.2, and the mean total CSI score was 3.7 (Table III). CSI item scores are shown in Table V. The most frequently endorsed item was “emotional adjustments” (55%), followed by “Some behaviour is upsetting” (51%). Approximately one-quarter (19 persons) of the next of kin reported a high level of caregiver strain (CSI score ≥7 points).

Caregiving – positive caregiver experiences

Nearly all of the next of kin responded that they found it important to care and were happy to do so, and perceived that their care was appreciated (97%) (Table VI). Most (64%) reported having enough time



Abbreviation: SCI, Spinal Cord Injury.

Fig. 1. Flow chart of participants in the survey of next of kin of individuals with spinal cord injury (SCI).

Table I. Descriptive characteristics of persons with spinal cord injury (SCI) related to next of kin responders ("Participating"), and those who were asked to provide contact information on next of kin

Characteristics of persons with SCI	Participating[*] (*N* = 73)	Asked persons with SCI[**] (*N* = 266)	*p*-value[a] for comparison of responders with asked persons with SCI
Age, years, Mean (SD)	59 (17.2)	57 (15.9)	0.5734
Sex, *N* (%)			0.118
Male	47 (64)	196 (74)	
Female	26 (36)	70 (26)	
Impairment groups (Neurological level and AIS), *N* (%)			0.292
Tetraplegia, AIS A–C	10 (14)	24 (9)	
Tetraplegia, AIS D–E	25 (34)	77 (29)	
Paraplegia, AIS A–C	18 (25)	58 (22)	
Paraplegia, AIS D–E	20 (27)	103 (39)	
Unknown or not applicable	0 (0)	4 (2)	
Time since discharge, years, Mean (SD)	4.2 (1.8)	4.5 (1.9)	0.3467
Cause of injury, *N* (%)			0.847
Traumatic	43 (59)	160 (60)	
Non-traumatic	30 (41)	106 (40)	

[*] Persons with SCI related to next of kin participating in the current study.

[**] Persons with SCI who were asked to provide contact information for next of kin.

[a] *p*-value from *t*-test for continuous and χ^2 test for categorical, with Fisher's exact test for impairment groups.

SCI: spinal cord injury; SD: standard deviation; AIS: American Spinal Injury Association Impairment Scale.

for themselves, but this proportion was considerably lower (30%) among next of kin caring for a person with the most severe impairment (tetraplegia AIS A–C).

Participation

The mean USER-Participation Frequency score was 39.3 (Table III). The mean vocational sub-score was 30.0 (SD 11.9), and the mean leisure and social activity sub-score 48.7 (SD 13.5) (detailed scores in Table SI).

Quality of life

For life satisfaction, the mean WHO QoL-5 score was 19.9 (Table III, detailed scores in Table SII). Four in 5 (78%) rated their QoL good or very good. For mental health, the mean MHI-5 score was 78.0 (Table III, detailed scores in Table SIII).

Table II. Descriptive characteristics of the next of kin of persons with spinal cord injury (N = 73)

Characteristics	
Age, years, Mean (SD)	56.4 (14.7)
Age groups, years, *N* (%)	
<55	28 (38)
55–67	29 (40)
>67	16 (22)
Sex, *N* (%)	
Male	20 (27)
Female	53 (73)
Level of education, *N* (%)	
Primary	8 (11)
Middle	25 (34)
Higher	40 (55)
Vocational status, *N* (%)	
Currently working or student	46 (63)
Retirement pension	20 (27)
Social welfare recipient	7 (10)
Personal income (Norwegian kroner per year), *N* (%)	
Below 500,000	36 (51)
500,000 and above	34 (49)
Relation to person with SCI, *N* (%)	
Partner	53 (73)
Family or other	20 (27)
Living together with person with SCI, *N* (%)	
Yes	53 (73)
No	20 (27)

SCI: spinal cord injury; SD: standard deviation.

Regression analyses

Table III shows the results of the regression analyses. Only a few of the characteristics showed significant associations with the various life areas. Next of kin in the retirement age group (>67 years) reported higher life satisfaction (WHOQoL-5) and less caregiver strain (CSI) compared with those in the other age groups. Those having a middle level of education provided more support and had higher levels of caregiver strain (CSI) compared with those with a primary and a higher level of education. Female next of kin tended to report higher levels of overall burden (SRB) than males. The frequency of participation increased with higher levels of education and higher income. Next of kin who were social welfare recipients showed lower participation scores compared with those working.

Being the next of kin of a person in impairment group tetraplegia AIS A–C (most severe disability) was associated with reporting higher objective burden of care. Otherwise, no consistent patterns were found between SCI injury characteristics and the life areas reported by next of kin.

DISCUSSION

In this survey of 73 next of kin, investigating how they experience various life areas, 3 out of 4 next of kin reported good mental health and life satisfaction. All participants considered it important to care, and almost all were happy to do so. Nevertheless, one-quarter of next of kin experienced high levels of subjective

Table III. Multivariable regression analyses adjusted for sex and age[a]: objective burden, subjective burden, participation and quality of life according to characteristics of next of kin and injury characteristics of the related person with spinal cord injury (N = 73[b])

Characteristics		Objective burden		Subjective burden				Participation		Quality of life			
		Support Score (Range 1–4)		Caregiver Strain Index (CSI) (Range 0–13)		Caregiver burden (SRB) (Range 0 –10)		USER-P frequency (Range 0-100)		Life satisfaction (WHO QoL-5) (Range 5–25)		Mental health (MHI-5) (Range 0–100)	
Variable	*N* (%)	Mean (95% CI)	*p*-value	Mean (95% CI)	*p*-value	Mean (95% CI)	*p*-value	Mean (95% CI)	*p*-value	Mean (95% CI)	*p*-value	Mean (95% CI)	*p*-value
Mean score (SD)		1.6 (0.5)		3.7 (3.4)		3.2 (2.8)		39.3 (9.0)		19.9 (2.9)		78.0 (13.8)	
Demographic and social variables next of kin													
Age-groups, years													
< 55	28 (38)	1.5 (1.3–1.7)	Ref	4.3 (3.0–5.5)	Ref	2.8 (1.8–3.9)	Ref	38.6 (35.3–41.9)	Ref	19.0 (17.9–20.1)	Ref	75.0 (69.9–80.1)	Ref
55–67	29 (40)	1.7 (1.6–1.9)	0.102	4.3 (3.1–5.5)	0.991	3.5 (2.5–4.6)	0.352	42.0 (38.7–45.3)	0.153	20.3 (19.2–21.3)	0.106	78.4 (73.4–83.5)	0.344
> 67	16 (22)	1.6 (1.3–1.8)	0.878	1.7 (0.1–3.4)	0.017[c]	3.3 (1.9–4.6)	0.627	35.8 (31.4–40.2)	0.311	21.0 (19.6–22.4)	0.029[c]	82.5 (75.7–89.3)	0.084
Sex													
Male	20 (27)	1.7 (1.4–1.9)	Ref	2.7 (1.2–4.2)	Ref	2.2 (1.0–3.5)	Ref	39.8 (35.7–43.9)	Ref	20.2 (18.9–21.5)	Ref	76.5 (70.4–82.6)	Ref
Female	53 (73)	1.6 (1.5–1.7)	0.709	4.1 (3.2–5.0)	0.124	3.6 (2.8–4.3)	0.072	39.2 (36.7–41.7)	0.808	19.8 (19.0–20.6)	0.650	78.6 (74.8–82.3)	0.572
Level of education													
Primary	8 (11)	1.3 (0.9–1.6)	Ref	1.7 (0–4.0)	Ref	3.3 (1.3–5.3)	Ref	33.5 (27.2–39.8)	Ref	19.2 (17.2–21.3)	Ref	81.8 (72.0–91.6)	Ref
Middle	25 (34)	1.8 (1.6–2.0)	0.005[c]	4.6 (3.3–5.9)	0.034[c]	3.6 (2.5–4.8)	0.773	37.2 (33.7–40.7)	0.303	19.2 (18.0–20.4)	0.954	77.3 (71.8–82.8)	0.427
Higher	40 (55)	1.6 (1.4–1.7)	0.122	3.6 (2.5–4.7)	0.147	2.9 (2.0–3.8)	0.687	41.8 (39.0–44.6)	0.019[c]	20.5 (19.6–21.4)	0.264	77.7 (73.3–82.1)	0.456
Vocational status													
Currently working or student	46 (63)	1.6 (1.4–1.8)	Ref	3.9 (2.8–5.0)	Ref	3.0 (2.1–3.8)	Ref	41.3 (38.6–44.0)	Ref	19.9 (18.9–20.9)	Ref	77.5 (73.1–81.9)	Ref
Retirement pension	20 (27)	1.5 (1.3–1.8)	0.651	3.1 (1.2–4.9)	0.504	3.2 (1.8–4.7)	0.762	38.7 (34.1–43.3)	0.370	20.4 (18.8–22.0)	0.629	79.7 (72.2–87.2)	0.652
Social welfare recipient	7 (10)	2.0 (1.6–2.4)	0.064	4.7 (2.1–7.3)	0.575	4.6 (2.5–6.7)	0.162	28.1(21.6–34.5)	< 0.001[c]	18.8 (16.5–21.0)	0.361	76.7 (66.1–87.2)	0.885
Personal income (Norwegian kroner per year)													
Below 500,000	36 (51)	1.7 (1.5–1.8)	Ref	3.5 (2.3–4.7)	Ref	3.3 (2.4–4.2)	Ref	37.8 (35.1–40.6)	Ref	19.4 (18.4–20.3)	Ref	79.6 (74.9–84.2)	Ref
500,000 and above	34 (49)	1.6 (1.4–1.8)	0.551	4.0 (2.8–5.2)	0.566	3.1 (2.1–4.0)	0.733	42.2 (39.3–45.0)	0.034[c]	20.5 (19.4–21.5)	0.123	77.1 (72.3–81.9)	0.468
Relation to patient													
Partner	53 (73)	1.7 (1.5–1.8)	Ref	4.1 (3.2–5.0)	Ref	3.4 (2.6–4.2)	Ref	38.2 (35.7–40.7)	Ref	19.8 (19.0–20.6)	Ref	77.9 (74.1–81.7)	Ref
Family or other	20 (27)	1.5 (1.2–1.7)	0.106	2.8 (1.2–4.3)	0.153	2.6 (1.4–3.9)	0.300	42.3 (38.2–46.4)	0.101	20.2 (18.9–21.6)	0.593	78.3 (72.0–84.5)	0.927
Injury characteristics of the related person with SCI													
Time since discharge													
4 years or less	36 (49)	1.6 (1.5–1.8)	Ref	3.5 (2.4–4.7)	Ref	3.1 (2.2–4.0)	Ref	39.0 (35.9–42.0)	Ref	19.7 (18.8–20.7)	Ref	79.2 (74.7–83.8)	Ref
More than 4 years	37 (51)	1.6 (1.5–1.8)	0.999	3.9 (2.8–5.0)	0.620	3.3 (2.4–4.2)	0.744	39.7 (36.7–42.7)	0.731	20.1 (19.1–21.1)	0.594	76.8 (72.3–81.3)	0.460
Impairment groups (level and AIS)													
Tetraplegia A,B,C	10 (14)	2.1 (1.8–2.4)	Ref	4.7 (2.6–6.8)	Ref	3.5 (1.8–5.3)	Ref	43.2 (37.4–49.0)	Ref	20.9 (19.0–22.7)	Ref	73.2 (64.6–81.9)	Ref
Tetraplegia D	25 (34)	1.4 (1.2–1.6)	< 0.001[c]	2.5 (1.1–3.8)	0.072	2.3 (1.2–3.4)	0.216	38.5 (34.8–42.2)	0.180	20.5 (19.3–21.7)	0.712	77.0 (71.5–82.5)	0.471
Paraplegia A,B,C	18 (25)	1.7 (1.5–1.9)	0.012[c]	3.5 (2.0–5.1)	0.362	3.7 (2.4–5.0)	0.877	39.2 (34.9–43.6)	0.276	19.0 (17.6–20.4)	0.104	78.9 (72.5–85.4)	0.295
Paraplegia D	20 (27)	1.6 (1.4–1.8)	0.003[c]	5.0 (3.5–6.4)	0.842	3.7 (2.5–4.9)	0.888	38.5 (34.4–42.6)	0.192	19.6 (18.4–20.9)	0.274	80.8 (74.7–86.9)	0.157

USER-P freq: Frequency 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; SCI: spinal cord injury; AIS: American Spinal Injury Association Impairment Scale; Ref: reference.

[a] All variables except sex and age were adjusted for sex, age.

[b] *N* vary from 69 to 73 for each variable due to missing data, or preferring not to answer.

[c] *p*-value < 0.05 from linear regression.

Table IV. Objective burden of care: Types of support "often" or "always" given by next of kin to persons with spinal cord injury according to the injury group of related persons with spinal cord injury ($N = 73$). More than 1 type of support could be given

	Injury group of related persons with SCI				
Type of support	All	Tetraplegia AIS A–C ($N = 10$)	Tetraplegia AIS D ($N = 25$)	Paraplegia AIS A–C ($N = 18$)	Paraplegia AIS D ($N = 20$)
ADL support, *N* (%)					
Preparing meals	32 (44)	8 (80)	6 (24)	9 (50)	9 (45)
Outdoor transportation	17 (23)	2 (20)	6 (24)	4 (22)	5 (25)
Various helping hands	15 (21)	7 (20)	3 (12)	4 (22)	1 (5)
Dressing	10 (14)	4 (40)	3 (12)	1 (6)	2 (10)
Transfer	10 (14)	5 (50)	2 (8)	1 (6)	2 (10)
Washing/showering	9 (12)	2 (20)	0 (0)	3 (17)	4 (20)
Grooming	6 (8)	3 (30)	1 (4)	1 (6)	1 (5)
Communication	5 (7)	2 (20)	1 (4)	2 (11)	0 (0)
Eating/drinking	5 (7)	2 (20)	0 (0)	3 (17)	0 (0)
Bladder	4 (5)	2 (20)	1 (4)	1 (6)	0 (0)
Bowels	4 (5)	2 (20)	0 (0)	1 (6)	1 (5)
Toileting	4 (5)	2 (20)	0 (0)	1 (6)	1 (5)
Moving around indoors	3 (4)	1 (10)	1 (4)	1 (6)	0 (0)
Other practical support, *N* (%)					
Visiting doctor	12 (16)	3 (30)	2 (8)	3 (17)	4 (20)
Arranging for care or support	11 (15)	2 (20)	4 (16)	3 (17)	2 (10)
Supplying medication	10 (14)	6 (60)	3 (12)	1 (6)	0 (0)
Supplying ADL materials	8 (11)	2 (20)	3 (12)	2 (11)	1 (5)
Arranging for adaptations	7 (10)	2 (20)	2 (8)	1 (6)	2 (10)
Arranging for adaptive devices	7 (10)	2 (20)	2 (8)	1 (6)	2 (10)
Administrate medication	6 (8)	3 (30)	1 (4)	2 (11)	0 (0)
Putting on splints or orthoses	4 (5)	0 (0)	1 (4)	1 (6)	2 (10)
Performing exercises	2 (3)	0 (0)	0 (0)	1 (6)	1 (5)
Emotional support, *N* (%)					
Comforting, enlivening	27 (37)	5 (50)	5 (20)	5 (28)	12 (60)
Learning to live with the SCI	20 (27)	4 (40)	4 (16)	5 (28)	7 (35)

SCI: spinal cord injury; ADL: activities of daily living; AIS: American Spinal Injury Association Impairment Scale.

burden, as measured by CSI, especially related to emotional adjustments.

Only a few of the studied characteristics showed significant associations with different life areas, such as that those of working age and having a middle level of education had higher levels of caregiver strain, and that female next of kin tended to express higher levels of overall burden than males. The only SCI injury characteristic associated with a life area of next of kin was that next of kin of a person in the impairment group tetraplegia AIS A–C (most severe disability) reported a higher objective burden of care.

Life areas most influenced

A literature review regarding the impact of SCI on the QoL of family members showed that depression, anxiety, and reduced satisfaction with life were commonly reported (9). This is in contrast with the findings of the current study, in which 4 in 5 (78%) next of kin rated their QoL good or very good, and their mean mental health score was similar to this score among the general population in Norway (MHI-5 score of 79.5) (30). Furthermore, many reported positive caregiving experiences. Although few studies have investigated whether caregiving represents meaning and purpose

Table V. Proportion of next of kin answering "Yes" on the items of the Caregiver Strain Index according to the impairment group of related persons with spinal cord injury ($N = 73$)

	Injury group of related persons with SCI				
Caregiver Strain Index item, *N* (%)	All	Tetraplegia AIS A–C ($N = 10$)	Tetraplegia AIS D ($N = 25$)	Paraplegia AIS A–C ($N = 18$)	Paraplegia AIS D ($N = 20$)
Emotional adjustments	40 (55)	6 (60)	11 (44)	10 (56)	13 (65)
Behaviour upsetting	37 (51)	5 (50)	10 (40)	7 (39)	15 (75)
Changes in personal plans	30 (41)	5 (50)	5 (20)	9 (50)	11 (55)
Confining	24 (33)	7 (70)	5 (20)	5 (28)	7 (35)
Physical strain	23 (32)	4 (40)	5 (20)	6 (33)	8 (40)
Sleep disturbed	23 (32)	4 (40)	3 (12)	6 (33)	10 (50)
Family adjustments	21 (29)	7 (70)	2 (8)	5 (28)	7 (35)
Recipient's change upsetting	20 (27)	1 (10)	8 (32)	4 (22)	7 (35)
Other demands on time	16 (22)	3 (30)	3 (12)	3 (17)	7 (35)
Work adjustments	13 (18)	2 (20)	1 (4)	2 (22)	6 (30)
Feeling completely overwhelmed	12 (16)	3 (30)	5 (20)	2 (11)	2 (10)
Inconvenient	7 (10)	2 (20)	1 (4)	1 (6)	3 (15)
Financial strain	6 (8)	0 (0)	1 (4)	1 (6)	4 (20)

SCI: spinal cord injury; AIS: American Spinal Injury Association Impairment Scale.

Table VI. Number and percentage of next of kin answering "Yes" on the positive subscale of the Caregiver Strain Index Expanded

	Caregivers answering "Yes", *N* (%)				
Item	All (*N* = 73)	Tetraplegia AIS A–C (*N* = 10)	Tetraplegia AIS D (*N* = 25)	Paraplegia AIS A–C (*N* = 18)	Paraplegia AIS D (*N* = 20)
Taking care is important	73 (100)	10 (100)	25 (100)	18 (100)	20 (100)
Recipient appreciates my care	71 (97)	10 (100)	25 (100)	16 (89)	20 (100)
I am happy to care	69 (95)	9 (90)	24 (96)	16 (89)	20 (100)
I handle the care fine	63 (86)	8 (80)	20 (80)	15 (83)	20 (100)
I have enough time for myself	47 (64)	3 (30)	19 (76)	11 (61)	14(70)

AIS: American Spinal Injury Association Impairment Scale.

(31), it has been shown that partners of persons with SCI who indicated positive effects of caregiving report better mental health (32). More research on the positive aspects of caregiving in future research is therefore warranted to increase awareness and to clarify how this contributes to the QoL of caregivers.

ADL and other practical support were given more often by next of kin of persons with serious disability, while fewer differences were seen between the groups with regard to emotional support. Similar findings were reported in 2 Dutch studies (1, 4). Although next of kin in the current study provided less support to persons with a less severe injury, compared with a previous study including only those who use wheelchairs (4), the proportions that provided support with outdoor transportation were similar (approximately 1 in 4). One reason is that outdoor transportation may be more challenging for disabled people in Norway, due to the demographics of Norway, with long distances, and long winters with much snow.

This study showed that emotional support was one of the types of support provided most, and emotional adjustments were the most frequently perceived strain, but that the severity of the SCI did not seem to influence either. Similar results have been found in other caregiver studies, e.g. advanced cancer (20), but this has not been reported in other SCI studies. This finding could be explained by an association between mental health of the patient and mental health of the next of kin (4), as they have a close relationship and are likely to influence each other.

Impact of next of kin characteristics

Next of kin of working age and with a middle level of education experienced more subjective burden compared with those who were retired or with higher or lower education. This is the opposite of the findings of a study by Post et al., in which the researchers concluded that the increasing age of partners was a significant predictor of caregiver burden (1). A possible explanation is that elderly persons with SCI in Norway receive paid support more often than those in the Netherlands, thus reducing the burden on next of kin. Alternatively, the use of different measures could have caused this difference. A literature review on the common determinants of caregiver burden in Western countries showed that the age of the caregiver was not a consistent predictor of caregiver burden (33).

One-quarter of the current participants experienced high levels of burden, lower than the 43% in a study among Dutch persons with SCI using a wheelchair (4), but similar to the results from another Dutch SCI study (5). The current finding, that female carers tended to report higher levels of overall burden, was also found in a literature review (33) and other SCI caregiver studies (1). This sex difference in caregiving burden could be related to women experiencing more secondary stressors (relational and financial problems, problems combining different tasks) (34).

Impact of SCI characteristics

Objective burden was the only life area of the next of kin that was influenced by the severity of the injury. Being the next of kin of a person with most severe disability (tetraplegia AIS A–C) was associated with reporting higher objective burden of care compared with next of kin of a person with less severe disability (paraplegia A–D or tetraplegia D). This finding is in line with findings from another study, which found that partners of individuals with tetraplegia provided support more often (4). However, they did not distinguish between the level of completeness (AIS A, B, C or D) within the tetraplegia group (4). Notably, next of kin of persons with paraplegia D tended to report almost similar results for subjective burden of care compared with next of kin of persons with tetraplegia AIS A–C. This finding was unexpected because other studies have indicated a strong association between the severity of disability, level of neurological injury, and the subjective burden of care (1, 35, 36). An explanation could be that individuals with less severe disability experience similar "hidden disabilities", such as incontinence and pain, as their more severely disabled counterparts (37).

Other factors influencing life areas

Life areas of next of kin could be influenced by other factors, such as secondary conditions, coping behaviour, mood or occupational status of the person with SCI. Findings in the study of Conti et al. from Italy indicated that a reduction in secondary SCI conditions, such as chronic pain and urinary tract infections, was related to less caregiver burden (38). Khazaeipour et al. found in a study from Iran that caregivers' burden was lower when the related person with SCI had a job (36). Thus, more research is needed to gain a more comprehensive understanding of how the life of those who are next of kin to a person with SCI is experienced and of which factors influence this.

Study strengths and limitations

This is the first study of next of kin of patients with SCI in Norway. The main strength is the comprehensive approach, covering several life areas and the linkage between patient data from a national medical SCI quality registry and survey data. In contrast to the majority of other SCI caregiver studies that are based on self-reported injury data provided by the caregiver (2), the current study collected injury data from a national medical SCI quality registry, hence these data are provided by clinicians. The current study combined the variables of the neurological level of injury and severity of the SCI into the recommended impairment categories (39). We have not found any SCI studies using this classification in relationship with caregiver burden. The involvement of a user representative as a member of our research team, who used personal experience to provide input to all steps, from the study design to reporting the results, has ensured an additional perspective on the findings and contributes toward providing people with SCI and their next of kin a voice in the research process.

This study has some limitations. Only 27% of the persons with SCI provided contact information for their next of kin and, consequently, the sample size was small. It might be that persons with SCI with a poor relationship with their next of kin were less interested in providing contact information. The non-responder analysis, however, showed that the persons with SCI whose next of kin participated were reasonable representative of persons with SCI in the register. However, the generalizability of the findings is hampered by the low response rate.

CONCLUSION

A significant majority of next of kin of persons with SCI experience that it is important to provide care, and they are happy to do so. Strengthening the experience of positive aspects of caregiving may enhance better mental health of next of kin. Nevertheless, one-quarter of next of kin in the current study experienced high levels of caregiver strain, especially regarding the need for emotional adjustments. Most at risk of caregiver strain are those of working age (< 67 years), and those with middle level of education. In order to reduce the subjective burden of care, it seems necessary to increase the ability of next of kin to cope with the emotional challenges related to their caregiver role. Interventions, such as caregiver counselling, could be useful to achieve this. Injury characteristics had only a minor impact on the various aspects of the lives of next of kin caregivers. Although more research is needed, the findings of this study indicate that there are aspects of the life of the closest next of kin of a person with SCI that should be considered during SCI patient rehabilitation, in order to support the everyday life of caregivers.

ACKNOWLEDGEMENTS

The authors thank all the study participants for their time and effort in responding to the questionnaire, and all persons with SCI who were willing to ask their closest next of kin to participate and to provide contact information. We further thank the 3 SCI specialized centres, at Haukeland University Hospital, St Olavs 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 Albert Verhagen, Ingrid Riphagen, Wilma van de Veen, and Lars-Magnus Halvorsen for their contribution to the translations. 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).

Conflicts of interest

The authors have no conflicts of interest to declare. AH is the leader of NorSCIR, but had no role in granting access to or delivery of the NorSCIR data.

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Table SI. Proportion of next of kin answering each of the categories on the single items in the frequency scale of Utrecht Scale for Evaluation of Rehabilitation-Participation (USER-P) score and the mean subscores of vocational activities and leisure and social activities

	N	Not at all, %	1–8 h per week, %	9–16 h per week, %	17–24 h per week, %	25–35 h per week, %	36 h or more per week, %	Mean subscore (Scale 0–100)
Vocational activities								30.0 (SD 11.9)
Paid work	73	34,3	4,1	4,1	4,1	11,0	42,5	
Unpaid work	73	46,6	41,1	6,9	2,7	2,7	0	
Education	72	93,1	4,2	1,4	1,4	0	0	
Household duties	73	0	28.8	35,6	19,2	6,9	9,6	
	N	Never, %	1–2 times last 4 weeks, %	3–5 times last 4 weeks, %	6–10 times last 4 weeks, %	11–18 timer last 4 weeks, %	19 times or more last 4 weeks, %	Mean subscore (Scale 0–100)
Leisure and social activities								48.7 (SD 13.5)
Sports or physical exercise	73	11.0	15.1	16.4	28.8	20.6	8.2	
Going out	71	16.9	36.6	38.0	7.0	1.4	0	
Daytrips and other outdoor activities	73	5.5	24.7	32.9	24.7	8.2	4.1	
Leisure activities at home	72	6.9	9.7	20.8	25.0	19.4	18.1	
Going to visit family or friends	73	9.6	17.8	43.8	23.3	2.7	2.7	
Family or friends coming to visit at your home	72	5.6	22.2	37.5	25.0	6.9	2.8	
Contacting others by telephone/computer	73	0	4.1	12.3	26.0	16.4	41.1	

SD: standard deviation.

Table SII. Proportion of next of kin answering each of the answering categories on the single items in the World Health Organization Quality of life assessment (WHOQoL-5)

Items	*N*	Very poor, %	Poor, %	Neither good nor poor, %	Good, %	Very good, %
How would you rate your QoL?	73	0	1.4	20.6	57.5	20.6
		Very dissatisfied, %	Dissatisfied, %	Neither satisfied/nor dissatisfied, %	Satisfied, %	Very satisfied, %
Satisfaction with health	73	0	12.3	13.7	57.5	16.4
Satisfaction with daily activities	73	2.7	5.5	9.6	52.1	30.1
Satisfaction with personal relationships	72	4.2	2.8	8.3	59.7	25.0
Satisfaction with living conditions	73	1.4	1.4	9.6	50.7	37.0

QoL: quality of life.

Table SIII. Proportion of next of kin answering each of the answering categories on the single items in the Mental Health subscale of the Medical Outcomes Study Short Form Health Survey (MHI-5)

Items	*N*	All of the time, last 4 weeks, %	Almost all of the time, last 4 weeks, %	Some of the time, last 4 weeks, %	A little of the time, last 4 weeks, %	None of the time, last 4 weeks, %
Nervous person	73	0.0	1.4	4.1	34.3	60.3
Felt down	73	0.0	0.0	4.1	21.9	74.0
Calm and peaceful	73	8.2	49.3	32.9	9.6	0.0
Downhearted and blue	73	0.0	1.4	9.6	42.5	46.6
Happy person	73	4.1	48.0	38.4	9.6	0.0

ISBN 978-82-326-5787-2 (printed ver.)
ISBN 978-82-326-5673-8 (electronic ver.)
ISSN 1503-8181 (printed ver.)
ISSN 2703-8084 (online ver.)

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Science and Technology