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Older adults with long-term spinal cord injury

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Older adults with long-term spinal cord injury

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Abstract

As a result of advances in healthcare and rehabilitation, many people with spinal cord injury (SCI) have lived several decades with their injury. Knowledge of living with long-term SCI into older age is limited, despite an increased focus on aging with SCI in research and clinical practice.

The overarching aim of this thesis was to describe and understand the life situation of older adults with long-term SCI in southern Sweden, with a specific focus on secondary health conditions (SHCs), activity limitations, depressive symptoms, participation in leisure time physical activity (LTPA) and life satisfaction.

This thesis is based on the first data collection of the Swedish Aging with Spinal Cord Injury Study (SASCIS), a longitudinal cohort study of persons aged 50 years or older and at least 10 years after SCI. Associations between variables were investigated using multivariable linear regression analyses.

The 123 participants (36 women, 87 men) in the SASCIS had a mean age of 63 years and a mean time since injury of 24 years. Injury levels ranged from C1 to L5, with 62% traumatic injuries and 31% complete injuries. A large majority (88%) used mobility devices, 53% were living in a relationship and 35% were working full-time or part-time. Bowel-related and bladder-related problems were reported by 32% and 44%, respectively, and 44% reported spasticity. Two thirds experienced moderate to severe pain in everyday life. Activity limitations, (i.e., physical independence), were on average moderate. A higher level and more severe SCI and spasticity were significantly associated with more activity limitations, explaining 68% of the variance.

A total of 5% were regarded as having probable depression and 29% had clinically relevant depressive symptoms. Sense of coherence (SOC), the coping strategy Acceptance, neuropathic pain and LTPA explained 53% of the variance in depressive symptoms. A stronger SOC was the strongest explanatory factor for fewer depressive symptoms. The on average strong SOC indicated favorable adjustment to living with SCI.

Participation in LTPA was low and almost one third did not participate in any LTPA. Sociodemographics, injury characteristics and SHCs explained less than 14% of the variance in LTPA participation. The use of a powered mobility device exhibited the strongest association with less participation in LTPA.

The participants rated their life satisfaction just above the midpoint between satisfied and dissatisfied with life. Sociodemographics, injury characteristics and SHCs explained 38% of the variance in life satisfaction, where having a partner was the strongest contributor to a high level of life satisfaction.

In conclusion, older adults with long-term SCI in southern Sweden exhibit a relatively high level of physical independence, a low presence of probable depression, a strong SOC and are generally satisfied with their lives. Many do not reach the amount or intensity of LTPA to achieve fitness benefits, and more research is needed to identify modifiable factors that can enhance their participation in LTPA. In clinical practice, pain and depressive symptoms should be evaluated, and participation in LTPA assessed and encouraged. Measures that strengthen psychological resources, provide adequate pain management and encourage participation in LTPA may support mental health. The results serve as a starting point for an increased understanding of the life situation of older adults with long-term SCI in Sweden, and can be used to inform rehabilitation planning and provide routines for follow-up.

Key words: Activities of Daily Living; Adaptation, Psychological; Aging, Depression; Exercise; International Classification of Functioning, Disability and Health; Rehabilitation; Sense of coherence; Spinal Cord Injuries

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Older adults with long-term spinal cord injury

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“What are the consequences of
my injury as I’m getting older?

It’s now, when my hair is grey,
that I’ve come to think of it.

I’m very aware that growing old
is not going to be easy for me,
with my disability”

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Abstract

As a result of advances in healthcare and rehabilitation, many people with spinal cord injury (SCI) have lived several decades with their injury. Knowledge of living with long-term SCI into older age is limited, despite an increased focus on aging with SCI in research and clinical practice.

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The 123 participants (36 women, 87 men) in the SASCIS had a mean age of 63 years and a mean time since injury of 24 years. Injury levels ranged from C1 to L5, with 62% traumatic injuries and 31% complete injuries. A large majority (88%) used mobility devices, 53% were living in a relationship and 35% were working full-time or part-time. Bowel-related and bladder-related problems were reported by 32% and 44%, respectively, and 44% reported spasticity. Two thirds experienced moderate to severe pain in everyday life. Activity limitations (i.e., physical independence) were on average moderate. A higher level and more severe SCI and spasticity were significantly associated with more activity limitations, explaining 68% of the variance.

A total of 5% were regarded as having probable depression and 29% had clinically relevant depressive symptoms. Sense of coherence (SOC), the coping strategy Acceptance, neuropathic pain and LTPA explained 53% of the variance in depressive symptoms. A stronger SOC was the strongest explanatory factor for fewer depressive symptoms. The on average strong SOC indicated favorable adjustment to living with SCI.

Participation in LTPA was low and almost one third did not participate in any LTPA. Sociodemographics, injury characteristics and SHCs explained less than 14% of the variance in LTPA participation. The use of a powered mobility device exhibited the strongest association with less participation in LTPA.

The participants rated their life satisfaction just above the midpoint between satisfied and dissatisfied with life. Sociodemographics, injury characteristics and SHCs explained 38% of the variance in life satisfaction, where having a partner was the strongest contributor to a high level of life satisfaction.

In conclusion, older adults with long-term SCI in southern Sweden exhibit a relatively high level of physical independence, a low presence of probable depression, a strong SOC and are generally satisfied with their lives. Many do not reach the amount or intensity of LTPA to achieve fitness benefits, and more research is needed to identify modifiable factors that can enhance their participation in LTPA. In clinical practice, pain and depressive symptoms should be evaluated, and participation in LTPA assessed and encouraged. Measures that strengthen psychological resources, provide adequate pain management and encourage participation in LTPA may support mental health. The results serve as a starting point for an increased understanding of the life situation of older adults with long-term SCI in Sweden, and can be used to inform rehabilitation planning and provide routines for follow-up.

List of papers

This thesis is based on the following studies, which have been reprinted with permission from the publishers. Throughout the thesis, the four studies are referred to with Roman numerals.

I. Jörgensen S, Iwarsson S, Norin L, Lexell J. The Swedish Aging with Spinal Cord Injury Study (SASCIS): Methodology and initial results. *PM&R; The journal of injury, function and rehabilitation.* 2016; 8: 667-677.

II. Jörgensen S, Iwarsson S, Lexell J. Secondary health conditions, activity limitations, and life satisfaction in older adults with long-term spinal cord injury. *PM&R; The journal of injury, function and rehabilitation.* 2017; 9: 356-366.

III. Jörgensen S, Martin Ginis KA, Lexell J. Leisure time physical activity among older adults with long-term spinal cord injury. *Spinal Cord* (e-pub ahead of print 2017 March 21; doi: 10.1038/sc.2017.26).

IV. Jörgensen S, Martin Ginis KA, Iwarsson S, Lexell J. Depressive symptoms among older adults with long-term spinal cord injury: Associations with secondary health conditions, sense of coherence, coping strategies and physical activity. *Journal of Rehabilitation Medicine* (e-pub ahead of print 2017 Aug 1; doi: 10.2340/16501977-2259).

Abbreviations

ADL	Activities of daily living
AIS	ASIA Impairment Scale[1]
ANOVA	Analysis of variance
ASIA	American Spinal Injury Association
CIC	Clean intermittent catheterization
CHIEF	Craig Hospital Inventory of Environmental Factors[2]
GDS-15	15-item Geriatric Depression Scale[3]
HE	Housing Enabler[4]
IASP	International Association for the Study of Pain
ICF	International Classification of Functioning, Disability and Health[5]
IPA	Impact on Participation and Autonomy[6]
LiSat-11	Life Satisfaction Questionnaire[7]
LTPA	Leisure time physical activity
PARA-SCI	Physical Activity Recall Assessment for People with Spinal Cord Injury[8]
SASCIS	Swedish Aging with Spinal Cord Injury Study
SCI	Spinal cord injury
SCIM III	Spinal Cord Independence Measure, third version[9]
SCI QL-23	Spinal Cord Injuries Quality of Life Questionnaire[10]
SCL CSQ	Spinal Cord Lesion-related Coping Strategies Questionnaire[11]
SD	Standard deviation
SHC	Secondary health condition
SOC	Sense of coherence[12]
SOC-13	13-item Sense of Coherence scale[13]
SWLS	Satisfaction With Life Scale[14]
VAS	Visual Analog Scale
WHO	World Health Organization
WUSPI	Wheelchair User's Shoulder Pain Index[15]

Definitions

Activity	The execution of a task or action by an individual.[5]
Activity limitations	Difficulties in executing activities.[5] Used here in the context of physical independence.
AIS A	Complete injury: No sensory or motor function is preserved in the lowest sacral segments (S4-S5).[1]
AIS B	Motor complete but sensory incomplete injury: Absence of motor function but preserved sensory function below the neurological level of injury, including the sacral segments S4-S5, and no preserved motor function more than three levels below the motor level on either side of the body.[1]
AIS C	Motor incomplete injury: Preserved motor function below the neurological level of injury with more than half of key muscles having a muscle grade less than 3 (3=active movement with full range of motion against gravity).[1]
AIS D	Motor incomplete injury: Preserved motor function below the neurological level of injury with at least half of key muscles having a muscle grade 3 or greater.[1]
AIS E	Normal sensory and motor function.[1]
Bladder-related problems	Problems related to neurogenic bladder dysfunction, such as urinary incontinence.
Body functions and structures	Physiological functions of body systems and anatomical parts of the body.[5]
Bowel-related problems	Problems related to neurogenic bowel dysfunction, such as bowel incontinence.
Clinically relevant depressive symptoms	A GDS-15 score of 5 or more.[16, 17]
Coping	Constantly changing cognitive and behavioral efforts to manage specific external and/or internal demands that are appraised as taxing or exceeding the resources of the person.[18]
Coping; Acceptance	Revaluation of life values.[11]

Coping; Fighting spirit	Efforts to minimize the effects of the SCI.[11]
Coping; Social reliance	A tendency towards dependent behavior.[11]
Depression	The two cardinal symptoms of depression are depressed mood and a loss of interest and pleasure.[19]
Disability	Umbrella term for impairments, activity limitations and participation restrictions.[5]
Environmental factors	The surrounding physical, social and attitudinal environment in which people live and conduct their lives.[5]
Healthy aging	The process of developing and maintaining the functional ability that enables well-being in older age.[20]
Impairments	Problems in body functions or structures.[5]
Leisure time physical activity	Physical activity performed during free time, such as walking, wheeling and exercise.[21]
Life satisfaction	A subjective judgement upon the current life situation in relation to the individual's own standards and expectations.[22]
Moderate-to-heavy LTPA	Leisure time physical activity of moderate to heavy intensity.
Neurological level of injury	The most caudal segment of the spinal cord with normal sensory and motor function on both sides of the body, provided that sensory and motor function is intact above this level.[1]
Neuropathic pain	Pain caused by a lesion or disease of the somatosensory nervous system.[23] Used here as pain at or below the neurological level of injury and described as tingling or burning.[24]
Nociceptive pain	Pain arising from musculoskeletal structures. Used here as pain in areas with preserved sensation, and described as dull or aching.[24]
Older adults with long-term SCI	At least 50 years old and have lived at least 10 years with SCI.

Paraplegia AIS A-C	SCI afflicting the thoracic or lumbar segments of the spinal cord (T1-L5) with a degree of impairment classified as AIS A-C.
Participation	Involvement in a life situation.[5]
Participation restrictions	Problems experienced in involvement in life situations.[5]
Personal factors	The particular background of a person's life and living that are not part of a health condition.[5]
Physical activity	Any bodily movement produced by skeletal muscles that results in energy expenditure.[25]
Probable depression	A GDS-15 score of 10 or more.[16]
Rehabilitation	A process aimed to enable people with disabilities to reach and maintain their optimal physical, sensory, intellectual, psychological and social functional levels.[26]
SCI severity groups	Three groups based on the level and severity of SCI: Tetraplegia AIS A-C, Paraplegia AIS A-C and AIS D of any injury level.
SHCs	Physical or psychological health conditions that are influenced directly or indirectly by the presence of a disability or underlying physical impairment.[27]
SOC	A salutogenic concept inferring that people's orientation towards life determines their ability to preserve good health despite external strains.[12]
Spasticity	A sign of dysfunction of the upper motor neuron pathway, characterized by increased muscle tone, exaggerated tendon reflexes and involuntary muscle contractions.[28]
Tetraplegia AIS A-C	SCI afflicting the cervical segments of the spinal cord (C1-C8) with a degree of impairment classified as AIS A-C.
Total LTPA	Leisure time physical activity of at least mild intensity.
VAS for pain	100 millimeter VAS ranging from 'no pain' to 'the worst pain imaginable'. Categorized as mild (5-44 mm), moderate (45-74 mm) and severe (75-100 mm).[29]

Preface

My first encounter with rehabilitation medicine and spinal cord injury (SCI) was during my first year at medical school. We were going to learn to perform a neurological examination and went to the rehabilitation medicine clinic at Skåne University Hospital in Höör (Orupssjukhuset). Our teacher was a short man in a white coat and our patient a young woman in a wheelchair. It was not the regular doctor-patient interaction, but more like a friendly conversation. I found it very appealing to work in an environment where there seemed to be enough time to meet the patient in his or her current situation. Little did I know then about the day-to-day clinical work, but rehabilitation medicine is in my opinion one of few medical specialties where this is still possible.

Several years later, in 2009, I listened to a lecture about rehabilitation after neurological injuries and diseases. The lecturer, who would later become my main supervisor, talked about being a "summer doctor" at the rehabilitation medicine clinic. I applied for the job and I was hooked. I developed an interest in SCI rehabilitation, and in the fall of 2009 I completed my master degree project about cardiovascular risk factors among older adults with long-term SCI. During this work, many of the participants were eager to tell their stories and expressed that there was limited knowledge about their situation, in healthcare as well as in society in general. The idea of conducting a larger, longitudinal project was born and in June 2010 I was accepted as a PhD student.

Writing my thesis was then far ahead and looking back I have gained some great experiences. I have spent time with 123 men and women who shared their experiences of living with SCI, which has undoubtedly reflected upon my clinical work. I have presented my research at major international conferences, supervised a Master student and co-authored several papers and a book chapter on physical activity and SCI. I have met colleagues from around the world, engaged in ongoing international collaborations and made good friends. I hope to continue to combine clinical work and research, and I believe that integrating my interest in SCI rehabilitation and the knowledge I have gained from writing this thesis is a good way to go forward.

Context of this thesis

This thesis was carried out within the Rehabilitation Medicine Research Group, Faculty of Medicine, the interdisciplinary Centre for Ageing and Supportive Environments (CASE), Lund University, and the Department of Neurology and Rehabilitation Medicine, Skåne University Hospital.

My starting point was a curiosity to learn more about the challenges of reaching older age with long-term SCI. Together with my main supervisor, professor Jan Lexell, I designed the research project the Swedish Aging with Spinal Cord Injury Study (SASCIS), a longitudinal cohort study of persons aged 50 years or older and at least 10 years after SCI. During the first years of my doctoral studies, I was involved in all parts of the SASCIS: designing the study protocol, putting together the study-specific questionnaire, selecting the assessment tools, writing the application to the Regional Ethical Review Board, applying for external grants and recruiting the participants. Together with another PhD-student, I planned and performed the data collection, and created the SASCIS database. For the four studies included in this thesis, I developed the research questions, performed the data analyses and wrote the papers, all in close collaboration with my supervisors and co-authors.

An international collaboration was developed during the work with this thesis. The assessment tool used for studying participation in leisure time physical activity (LTPA) was developed by a Canadian research group, led by professor Kathleen Martin Ginis, co-author of Studies III and IV. I had the opportunity to visit her research group in November 2016 and see at first-hand the ongoing work of developing SCI-specific international guidelines for physical activity.

This thesis is based on the first data collection of the SASCIS, and it provides a description of the life situation of older adults with long-term SCI in southern Sweden at a single point in time. I have conducted the studies in this thesis as a clinical scientist, with the ambition to arrive at clinically relevant implications and directions for future research. From our original study sample (n=123), 85 persons are now enrolled in the 2017 SASCIS follow-up. From the four studies included in this thesis, several research questions emerged that we hope to answer through the forthcoming data collection. This thesis thus serves as a starting point for a deeper understanding of aging with long-term SCI in Sweden.

Introduction

A spinal cord injury (SCI) can be a life-altering event that challenges many aspects of everyday life. The management of SCI as we know it was initiated by Sir Ludwig Guttmann at Stoke Mandeville Hospital, England, in the 1940s.[30] With a comprehensive approach to SCI care the 80% mortality rate[30] began to be reduced and Guttmann set the stage for the development of the standards of SCI care and rehabilitation of today. In this period, the perception of SCI changed from a condition with little hope for survival to the possibility for full adjustment to an independent and healthy life with a severe physical disability.[31, 32]

Most of the almost 300 men and women who sustain a traumatic or non-traumatic SCI in Sweden each year[33] can today be expected to live long lives. With the increased life expectancy among persons with SCI, aging with the injury has received increased attention in research and clinical practice. However, knowledge of living with long-term SCI into older age is limited.

The four papers comprising this thesis describe aspects of the life situation of older adults with long-term SCI in southern Sweden. The intention is to provide increased knowledge of what it is like to reach older age with long-term SCI, in order to inform rehabilitation planning and provide routines for follow-up.

Spinal cord injury

The spinal cord runs through the vertebrae of the spine and serves as the link between the brain and the body. Damage to the spinal cord affects the motor, sensory and autonomic signaling across the lesion site.[1] The injury can be traumatic or non-traumatic. Globally, the most common causes of traumatic SCI are motor vehicle accidents, followed by falls and acts of violence.[30] Non-traumatic SCI can be acquired or congenital, and the most common causes of acquired injuries in developed countries are tumors and degenerative diseases, whereas infections are more common in developing regions.[34]

A SCI results in varying motor, sensory and autonomic impairments depending on the level of injury and the severity (i.e., completeness) of the lesion. An injury that affects the cervical segments of the cord (C1-C8) results in tetraplegia, i.e.,

impairments of the upper and lower extremities, the pelvis and the trunk. An injury to the thoracic (T1-T12), lumbar (L1-L5) or sacral (S1-S5) segments of the spinal cord results in paraplegia, i.e., impairments of the lower extremities and depending on the level of injury, it may also involve the pelvis and the trunk.[1] Figure 1 depicts the organization of the spinal cord and the representation of major bodily functions in relation to the segments of the cord.

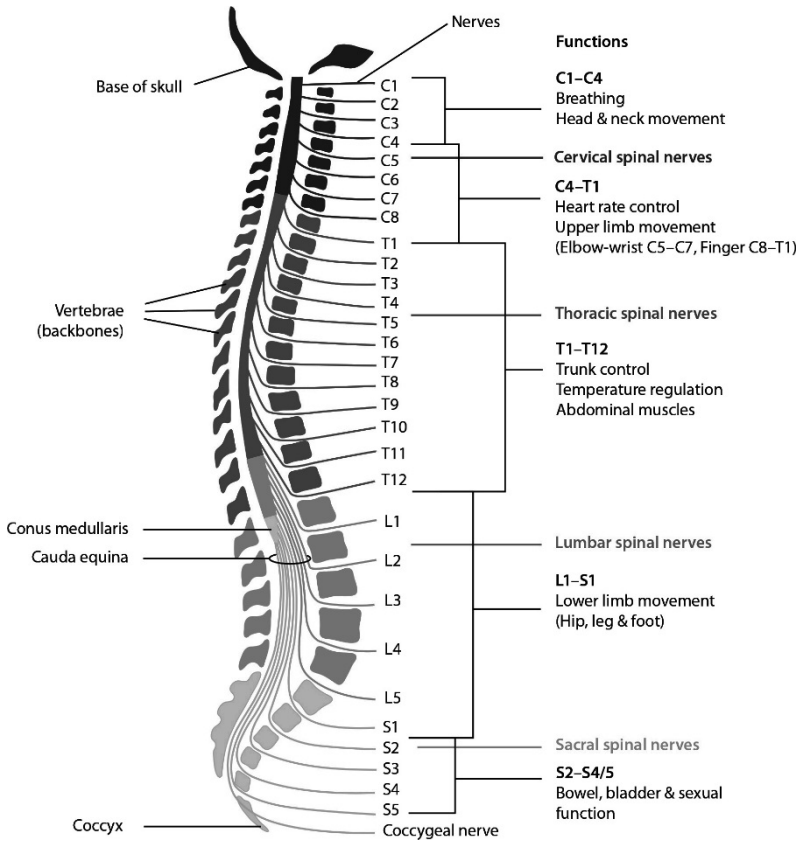

Figure 1.
Organization of the spinal cord. Reprinted with permission from International Perspectives on Spinal Cord Injury,[30] edited by Jerome Bickenbach et al. Understanding spinal cord injury, page 5, WHO (2013).

Continuous neurological assessments are performed in the initial phase after the injury to monitor improvement in function. This assessment includes determination of the neurological level of injury and the severity of injury. The neurological level of injury refers to the most caudal segment of the spinal cord with intact sensory and motor function,[1] and the severity of injury is classified according to the American Spinal Injury Association (ASIA) Impairment Scale (AIS),[1] as presented in Table 1.

Table 1.
Classification of a spinal cord injury according to the American Spinal Injury Association Impairment Scale (AIS).[1]

Classification	Degree of impairment
AIS A	Complete injury: No sensory or motor function is preserved in the lowest sacral segments (S4-S5).
AIS B	Motor complete but sensory incomplete injury: Absence of motor function but preserved sensory function below the neurological level of injury, including the sacral segments S4-S5, and no preserved motor function more than three levels below the motor level on either side of the body.
AIS C	Motor incomplete injury: Preserved motor function below the neurological level of injury with more than half of key muscles having a muscle grade less than 3. (3=active movement with full range of motion against gravity. Strength of muscle function is graded on a six-point scale from 0=total paralysis to 5=normal.)
AIS D	Motor incomplete injury: Preserved motor function below the neurological level of injury with at least half of key muscles having a muscle grade 3 or greater.
AIS E	Normal sensory and motor function.

There is no available cure for a damaged spinal cord but with adequate acute care, the secondary injury to the surrounding tissue can be minimized. Restitution of neurological function depends on the degree of impairment and most of the recovery typically occurs within the first three months after the injury.[35] Full recovery is rare for an injury initially considered complete (AIS A), whereas an incomplete injury has greater potential of restitution.[35]

Epidemiology

Globally, between 250 000 and 500 000 people sustain a SCI each year.[30] For traumatic SCI, the incidence in western European countries is approximately 16 per million per year,[36] and the corresponding number for non-traumatic SCI is 6 per million per year.[34] Traumatic SCI is at least twice as common among men and occurs predominantly among younger adults and in old age, where the latter is a result of an increased occurrence of falls in the older population.[30] In Sweden, the prevalence of traumatic SCI was in 2006 estimated at 5000 individuals.[37] In 2016, 286 persons (63% men) in Sweden sustained SCI (58% traumatic) requiring primary rehabilitation.[33] At discharge from primary rehabilitation, the majority had a thoracic/lumbar/sacral injury and AIS D was the most common severity of injury.[33]

Mortality and life expectancy

The most common causes of death initially after injury are respiratory complications.[38] For people living with SCI for a long time, the causes of death are similar to those in the general population, such as cardiovascular diseases, respiratory disorders and cancer.[39, 40] Life expectancy after SCI has greatly

improved, but it is still lower than in the non-injured population.[30, 41, 42] A shorter life expectancy is mostly seen in those with higher level and more severe injuries (based on the AIS) and in those injured at older ages.[42]

Rehabilitation after spinal cord injury

Persons sustaining SCI need support to adjust to the altered life situation in order to prevent complications and achieve the highest possible level of independence and life satisfaction.[30] A holistic approach to the management of the consequences of the injury is important and is provided by goal-oriented interdisciplinary rehabilitation.

According to the World Health Organization (WHO), rehabilitation is a process aimed to enable people with disabilities to reach and maintain their optimal physical, sensory, intellectual, psychological and social functional levels.[26] Rehabilitation provides disabled people with the tools they need to attain independence and self-determination.[26] The overarching goal of rehabilitation is thus to enable people to lead the life they desire in their specific context, despite the disability. In order to achieve this goal throughout the lifespan of people with SCI, more knowledge of the life situation of adults living into older age with the injury is needed.

The International Classification of Functioning, Disability and Health (ICF)[5] is the standard framework and common language in rehabilitation medicine.[43] The ICF was developed by the WHO and provides an integrative biopsychosocial view of disability.[43] According to the ICF,[5] functioning and disability are the results of the interaction between a health condition and contextual factors (i.e., personal and environmental factors). Disability is the umbrella term for impairments (i.e., problems in body functions and structures), activity limitations (i.e., difficulties in executing a task) and participation restrictions (i.e., problems experienced in involvement in life situations). Personal factors constitute the background of a person's life and living, and are features that are not part of a health condition; examples of these are gender, behavior and coping strategies. Environmental factors can be facilitators of, or barriers to functioning and comprise the surrounding physical, social and attitudinal environment. Most aspects of living with SCI can be incorporated into the ICF, which is why the ICF was chosen to guide the design of the studies in this thesis.

The rehabilitation process

The participants in this thesis were recruited from the SCI Unit at Skåne University Hospital, which is one of the largest specialized SCI units in Sweden. The unit admits 35 to 55 individuals each year for primary rehabilitation (30-35% women, 75-85% traumatic SCI), with an average length of stay of two to three months.[44]

The complex nature of SCI requires experienced, coordinated and resource-rich care systems to manage the lifelong consequences of the injury. There is ongoing advocacy for a centralization of SCI care and rehabilitation in Sweden,[45] but despite these efforts, SCI rehabilitation is today carried out at more than 20 different units across the country. Six of these are specialized SCI units where approximately 75% of all individuals with newly sustained injuries receive their primary rehabilitation.[33]

Primary rehabilitation

Admission to specialized SCI units shortly after injury has proven important for reducing the duration of hospitalization, complications and overall mortality.[46] The rehabilitation process consists of assessing the consequences of the injury, setting short-term and long-term goals, carrying out appropriate interventions and measuring the outcome.[47] The interdisciplinary team-based work is the core of this process.[47] This type of team work refers to the involvement of various health professionals who assess and treat the person according to common overall goals[48] that are coordinated into an ICF-based rehabilitation plan.[47] The process relies on group responsibility for the overall management planning, and the progress is documented and reported at regular team meetings.[48] The person with SCI and his or her family are active members of the team,[48] which is an empowerment process and an opportunity to convey knowledge about the consequences of the SCI.

The rehabilitation team at the SCI Unit at Skåne University Hospital consists of physicians, nurses, assistant nurses, physiotherapists, occupational therapists, social workers, a psychologist, a recreational therapist and a peer mentor. The team works in close collaboration with other disciplines, such as urologists to assess and manage bladder dysfunction, upper limb and hand reconstructive surgeons for nerve and tendon transfers, and plastic reconstructive surgeons for wound management.

Peer support and community peer-based rehabilitation approaches

Although SCI rehabilitation is comprehensive and highly specialized, persons with SCI can feel unprepared for the transition from hospital to community.[49] Peer mentors who have successfully faced a comparable experience can facilitate this transition as they provide counseling and share their experiences, knowledge and skills.[30, 48, 50] Peer support is associated with improved adjustment and community reintegration, and fewer medical complications.[50-52] In Sweden, many SCI Units have employed peer mentors and peer support is also provided through the non-

profit organization RG Active Rehabilitation. After the primary rehabilitation period, there are community peer-based programs that provide knowledge of life with SCI through interaction with more experienced peers.[53, 54] These programs include training camps and outdoor activities, with the intention to support independence and motivate people with SCI to reach their full potential.[53]

Return to work

An active vocational life after SCI is associated with longevity, enhanced community integration, better adjustment and a higher level of life satisfaction.[55-59] However, employment rates are lower for people with SCI compared to the general population.[60] In the Scandinavian countries, the employment rate for persons of working-age five years after injury is approximately 50%.[61]

To resume productive activities is an important goal for rehabilitation.[61] Assessments of opportunities for return to work and/or education often starts during primary rehabilitation and are conducted in collaboration with the employer, the Swedish Public Employment Agency (Arbetsförmedlingen), the Swedish Social Insurance Agency (Försäkringskassan) and other relevant actors.

Support from the Swedish society

To make everyday life easier and enable people with disabilities to live their lives on equal terms with others of the same age, several services and opportunities for support are available.[62] Examples are personal assistance and companion service, home-help services, assistive devices, housing adaptations and special housing, disability parking permits, car adaptations and special transportation services for those who are unable to use regular public transport.

Lifelong management of spinal cord injury

The SCI results in an increased susceptibility to complications in almost all organ systems. Lifelong follow-up at a specialized SCI unit is provided to minimize the risk of such complications, maintain function and community participation,[63] and ensure that the needs for support from healthcare and society are met. However, the literature offers no consensus on how this lifelong management should be conducted.[63] After discharge from primary rehabilitation at the SCI Unit at Skåne University Hospital, the person is enrolled in a lifelong follow-up program, as outlined in Figure 2.

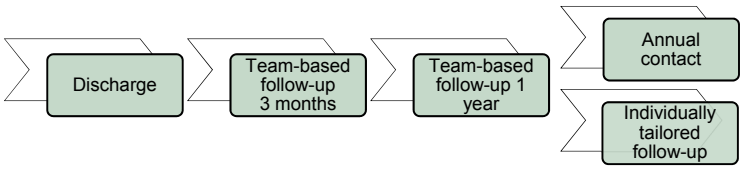

Figure 2.
Follow-up program provided by the SCI Unit at Skåne University Hospital.

The team-based follow-up visit typically lasts for three to four hours when the person with SCI meets with a rehabilitation physician, a physiotherapist, an occupational therapist and a social worker. Each team member assesses the person's needs and these assessments are summarized into a long-term plan. This plan can include future rehabilitation interventions, the need for contact with other disciplines and societal services, and scheduled follow-ups. The follow-up procedures are based on the same routines, regardless of the person's age and time since injury.

The SCI Unit provides secondary inpatient rehabilitation and outpatient care, and has a telephone service operated by a nurse offering guidance and counseling. Annual controls of kidney function, blood lipid profiles and fasting glucose are provided by the person's local primary healthcare center.

In addition to the specialized follow-up, people with SCI need access to healthcare services available to the general population.[30] Many medical conditions do not present with the regular signs and symptoms after SCI,[42] and teaching the person how to interpret signals from the "new body" is therefore an essential part of the rehabilitation process. As knowledge about the complexity of SCI can be limited among general healthcare professionals,[30, 64] SCI units can be used for consultation.

Older adults with long-term spinal cord injury

Population aging has become one of the major social transformations in the last decades.[65] The proportion of people over the age of 65 years in Sweden is steadily increasing and is currently estimated to be over 20% of the population.[66] In addition, more people are living into older age with a disability, placing demands on healthcare systems and society to meet their emerging needs.[65] Rehabilitation has been suggested as the key health strategy to support healthy aging in this growing population.[65]

Healthy aging is receiving much attention in policymaking, research and healthcare.[20, 67] According to the WHO, healthy aging is the process of developing and maintaining the functional ability that enables well-being in older age.[20] The functional ability is determined by the interaction between a person's physical and mental capacities and the surrounding environment, and represents the ability to do and to be what is perceived as valuable.[20] Healthy aging is thus a subjective experience and not merely the absence of disease or disability. The WHO definition of healthy aging draws on the ICF,[20, 67] and has many similarities with the overarching goal of rehabilitation. In its essence, the long-term management of SCI aims to enable healthy aging.

Spinal cord injury and age-related changes

Aging necessitates a constant re-adjustment for many people with SCI, which is imposed by the combination of a neurological injury and age-related changes affecting body systems, activity performance and participation in society.[40, 68, 69] There is evidence of accelerated aging following SCI,[39, 42, 70, 71] caused by years of cumulative stress on organ systems.[40] For example, the injury results in autonomic dysfunction and metabolic and body composition changes leading to an increased risk of early development of obesity and lifestyle-related diseases, such as cardiovascular disease and diabetes.[39, 72-74] Focusing on modifiable lifestyle-related risk factors is therefore an important part of the long-term management of SCI.

Aging with SCI has been the subject of many studies and reviews since the 1990s.[39, 42, 70, 71, 75, 76] There are some large longitudinal studies following people with SCI for several decades,[55, 77-79] but research focusing specifically on older adults with long-term SCI is scarce. One Swedish PhD thesis has provided knowledge on aspects of aging with SCI, where participation in everyday occupations and leisure activities was the point of interest.[80] To date, no comprehensive study of older adults with long-term SCI has previously been conducted in a northern European perspective.

The accelerated aging process after SCI, the susceptibility to complications and changed prerequisites for activity performance and participation in society are potentially more pronounced in people who have lived many years with the injury. Modifications of existing follow-up programs may therefore be warranted to meet their specific needs. To attain this, more knowledge of the life situation of older adults with long-term SCI is needed. The following sections describe aspects of living with SCI relevant for this thesis, all of which can be considered as factors of importance for healthy aging in this population.

Secondary health conditions

The paralysis after SCI is only the tip of the iceberg of the wide array of impairments and secondary health conditions (SHCs) that can occur after the injury. Jensen et al.[27] defined SHCs as physical or psychological health conditions that are influenced directly or indirectly by the presence of a disability or underlying physical impairment. This thesis focuses on neurogenic bowel and bladder dysfunction and related problems, spasticity and pain as they are common SHCs after SCI and regarded among the most important for those affected.[71, 81-84] These SHCs are also considered to restrict performance of activities of daily living (ADL) and valued activities, and to have a major impact on social relationships, mental health and overall well-being.[64, 81, 82, 85-89]

Neurogenic bowel and bladder dysfunction and related problems

The disruption of the autonomic control of the gastrointestinal tract results in impaired sensation of the need to defecate, prolonged colonic transit time, and impaired anorectal sensation and motor control.[87, 90] Establishing an effective bowel management routine is important for preventing severe constipation and incontinence. The SCI can disrupt the neural circuitry responsible for coordinating bladder filling and emptying.[88] Impairments include difficulty in sensing a full bladder, incontinence and a lack of coordination between the sphincter and the detrusor during micturition.[88, 91, 92] These impairments are associated with the risk of urological complications, such as urinary tract infections, stone formation and increased pressure in the urinary tract causing secondary renal damage.[91, 92] A thorough assessment of bladder functioning and introducing an appropriate method for bladder emptying are crucial for preventing these complications and achieving continence.[88, 92] Clean intermittent catheterization (CIC) has the lowest rate of complications and is the method of choice for people with inability to void spontaneously.[92] Conversely, indwelling catheters are associated with an increased risk of urethral strictures, infections, bladder stones and bladder cancer.[92, 93]

Spasticity

Spasticity is characterized by increased muscle tone, exaggerated tendon reflexes and involuntary muscle contractions which can be painful.[28] Spasticity can be beneficial as it counteracts muscle atrophy, increases peripheral blood circulation and can contribute to the ability to stand and walk.[28, 94] Conversely, it can impede independence in dressing, transferring and bowel and bladder management, and contribute to the development of contractures, pressure ulcers and pain.[28, 94]

Pain

Data on the occurrence of pain after SCI vary greatly, mainly due to methodological differences between studies. A recent review provides an estimation of an overall prevalence of about 60%.[95] Chronic pain after SCI has a negative impact on mood, sleep, social integration, activity performance and satisfaction with life.[85, 86, 96-98] Using the terminology of the International Association for the Study of Pain (IASP), post-SCI pain can be classified as nociceptive, neuropathic or other pain types.[24] Nociceptive pain occurs in regions with some preserved sensation, arises from musculoskeletal structures and is often described as dull or aching.[24] Neuropathic pain is caused by a lesion or disease of the somatosensory nervous system,[23] and is often described as burning, tingling and pricking.[24]

Other secondary health conditions

The SCI may also result in impaired sexual function, an increased risk of developing pressure ulcers and disorders of the respiratory tract including paresis of respiratory muscles and a predisposition to pulmonary infections.[94, 99, 100] Autonomic dysfunction after SCI can result in impaired regulation of blood pressure, core body temperature and heart rate. Individuals with injury levels at or above T6 may experience a potentially life-threatening increase in blood pressure as a response to stimuli below the level of injury, referred to as autonomic dysreflexia.[101]

The long-term perspective

SHCs result in an increased vulnerability to the effects of aging and some of these conditions may exacerbate with time.[40] However, results regarding the association between SHCs, age and duration of injury are inconclusive.[71] Recently, Adriaansen et al.[81] conducted one of few studies addressing SHCs in people with long-term SCI, and investigated associations with satisfaction with life. With regards to older adults with long-term SCI, even less is known about these associations. An increased knowledge of SHCs and their association with aspects of activity, participation and well-being across the lifespan of people with SCI is needed.[42] This knowledge can be used to identify SHCs of particular importance for older adults with long-term SCI, and guide the development of interventions to limit their impact.

Activity limitations

People with SCI often experience restrictions in mobility, self-care and other daily activities which may necessitate assistive devices and/or personal assistance to manage everyday life.[30] The degree of physical dependence is primarily associated with the level and severity of injury where those with a higher level and more severe injury require more support.[35] Performance of ADL can also be compromised due to SHCs, in particular pain and spasticity.[82] Rehabilitation aims to maintain and

improve preserved motor functions, limit the impact of SHCs and provide alternative strategies and techniques to overcome activity limitations.[30] The level of physical independence often improves over several years after the initial rehabilitation period.[102] However, a decline in function is to be expected after periods of restoration and maintenance.[103]

The long-term perspective

The SCI results in a limited reserve capacity to cope with the increased activity limitations caused by general aging.[104] The point when age-related decline becomes apparent will therefore be reached earlier in life.[40] Increasing age has been suggested to be more closely associated with decreased independence in daily activities than the level and severity of injury.[76] People with SCI experience increased physical demands that cause more wear and tear on the musculoskeletal system. With time, this can lead to degenerative joint changes, pain and weakness which may necessitate increased use of assistive devices and personal assistance.[40] Such changes can in turn evoke psychological reactions due to the loss of autonomy and physical independence.[40] An increased knowledge of activity limitations and associated factors among older adults with long-term SCI could provide an understanding of how to mitigate these negative processes.

Depressive symptoms and psychological resources

The SCI often requires adjustment to a new life situation and it is not surprising that feelings of distress and fear can arise. The prevalence of depression after SCI is difficult to estimate due to the use of different assessment tools and definitions of depression. One review[105] reported that 20-30% of people with SCI show signs of possible or probable depression, which is higher than in the general population.

Factors consistently associated with psychological adjustment and mental health after SCI are personal factors, such as the psychological resources sense of coherence (SOC) and coping strategies.[106-108] The salutogenic concept of SOC[12] infers that people's orientation towards life determines their ability to preserve good health despite external strains. People with a strong SOC are able to view life events as comprehensible, manageable and meaningful[12] and mobilize their available resources to handle strains.[106] Coping can be defined as constantly changing cognitive and behavioral efforts to manage specific external and/or internal demands that are appraised as taxing or exceeding the resources of the person.[18] Three specific coping strategies have been associated with adjustment to SCI. These are labeled: Acceptance (i.e., revaluation of life values), Fighting spirit (i.e., efforts to minimize the effects of the lesion) and Social reliance (i.e., a tendency towards dependent behavior).[11]

The long-term perspective

Depressive symptoms in older age in the general population are associated with increased disability and mortality.[109] Given the limited reserve capacities of older adults with long-term SCI, depressive symptoms can have far-reaching consequences for health and well-being. Research on the trajectory of depressive symptoms after SCI and the relationship with age and time since injury shows inconclusive results.[71, 105] Depressive symptoms appear to be associated with potentially modifiable factors, such as SHCs, SOC, coping strategies, and health behaviors.[86, 106-108, 110, 111] Few studies have specifically assessed older adults with long-term SCI, and knowledge of potentially modifiable factors associated with their mental health is largely lacking. With an increased knowledge in this area, we may be able to identify those at risk for depression and provide measures to reduce depressive symptoms.

Leisure time physical activity

Physical activity can be defined as any bodily movement produced by skeletal muscles that results in energy expenditure.[25] As such, physical activity encompasses a wide range of activities from exercise to work and household activities.[25] People with SCI are considered one of the most physically inactive groups in society.[112, 113] The sedentary lifestyle contributes to deconditioning and an increased risk of cardiovascular disease and SHCs, such as pain and spasticity.[112]

There is strong evidence for beneficial effects of physical activity on muscle strength, fitness and cardiometabolic health after SCI.[114-116] There is also evidence of positive associations between physical activity and physical independence, mood and life satisfaction.[117, 118] Leisure time physical activity (LTPA) is the type of physical activity associated with these beneficial effects, comprising activities performed during free time, such as wheeling and walking, exercise and recreational activities.[21] Habitual LTPA is recommended for people with SCI[114] and a recent systematic review[115] has provided the evidence base to inform an updated, international SCI-specific physical activity guideline. For adults with chronic SCI, at least 20 minutes of moderate to heavy intensity aerobic physical activity twice per week, and strength training exercises twice per week, is required to reach fitness benefits.[115] Thirty minutes three times per week of at least moderate intensity aerobic activity is required for cardiometabolic benefits.[115]

The long-term perspective

Participation in LTPA decreases with age among people with SCI,[119, 120] and the sedentary lifestyle contributes further to the development of age-related comorbidities.[112] There are well-known benefits of participation in LTPA among

older adults in the general population, such as increased longevity, improved physical health, fitness, mobility and independence, and increased community involvement.[20] Perhaps the most intriguing beneficial effect of LTPA is the one on mental health and cognition.[20] These benefits are likely to also exist in older adults with long-term SCI, but no studies are available that provide information about their activity levels, factors associated with their participation in LTPA or benefits of a physically active lifestyle. Such knowledge is essential for being able to use physical activity in health promotion strategies tailored for this group.

Life satisfaction

Self-reported psychological well-being, including life satisfaction, is associated with health and longevity, and is therefore important to consider in older ages.[121] Life satisfaction refers to a subjective judgement upon the current life situation in relation to the individual's own standards and expectations,[22] and includes an evaluation of the extent to which life goals have been achieved.[122] Life satisfaction is typically at a low level initially after SCI but then improves to a higher and stable level, albeit lower than in the general population.[105] Life satisfaction can thus be regarded as closely associated with the adaptation process after injury, and as an overarching goal of rehabilitation.

The long-term perspective

Older age is associated with an increased risk of disease, social changes and personal losses, which may be expected to result in a lower level of life satisfaction.[20] A great deal of research actually points to the opposite and shows increased satisfaction with life in older ages.[121] Similarly, despite the seemingly never-ending hardships of living with SCI, there is evidence that people who have lived many years with the injury are well adjusted and report rather high and stable levels of life satisfaction.[55, 77, 123-125]

Life satisfaction does not seem to be associated with the level and severity of SCI but instead with marital status, employment, perceived health, time since injury and SHCs.[57, 81, 124, 126-128] These associations have mostly been studied in samples including younger persons and whether they hold true also in older adults with long-term injury is yet to be determined. Levels of life satisfaction in this population can be regarded as an indicator of how rehabilitation, healthcare and society provide support for these persons. Knowledge of factors associated with life satisfaction among older adults with long-term SCI can thereby be used to guide the development of follow-up programs to improve the long-term management and increase levels of life satisfaction.

Rationale

When this thesis project was initiated in 2010, little was known about older adults with long-term physical impairments.[129] The complexity of living into older age with SCI was acknowledged, emphasizing the need for more research, education, communication and coordination to proactively address age-related decline and disability.[130] Six years later, the effects of aging were still considered among the top ten prioritized areas in SCI research.[131]

As an increase in the global life expectancy is anticipated in the next decades[132] and further advances in rehabilitation and healthcare are to be expected, the proportion of older adults living with SCI for many years will continue to increase. To support their healthy aging, there is a need to ensure that aspects of their health and well-being are considered in rehabilitation interventions and long-term management.

Older adults with long-term SCI constitute a vulnerable group who not only face the lifelong consequences of a neurological disability but also the challenges of aging. Knowledge about living with SCI for a long time has increased but cultural, contextual and methodological differences make it challenging to relate findings across national contexts and over several decades.

No comprehensive, population-based studies of older adults with long-term SCI have been conducted from a northern European perspective, and there is no consensus on how to design rehabilitation interventions and follow-up programs to meet their specific needs. A greater understanding of the life situation of older adults with long-term SCI in southern Sweden is a first step towards evidence-based management. More specifically, knowledge about SHCs, activity limitations, depressive symptoms, participation in LTPA and life satisfaction can be used to inform rehabilitation planning and provide routines for follow-up.

Aims

The overarching aim of this thesis was to describe and understand the life situation of older adults with long-term SCI in southern Sweden, with a specific focus on SHCs, activity limitations, depressive symptoms, participation in LTPA and life satisfaction.

Specific aims

In a cohort of men and women aged 50 years or older and at least 10 years after SCI:

- describe sociodemographics, injury characteristics and the occurrence of SHCs (i.e., neurogenic bowel and bladder dysfunction and related problems, spasticity and pain);
- describe activity limitations, and investigate the associations with sociodemographics, injury characteristics and SHCs;
- describe the presence of depressive symptoms and investigate the associations with sociodemographics and injury characteristics, and determine how potentially modifiable factors, i.e., SHCs, SOC, coping strategies and LTPA, are associated with depressive symptoms;
- describe participation in LTPA, and investigate the associations with sociodemographics, injury characteristics and SHCs;
- describe life satisfaction and investigate the associations with sociodemographics, injury characteristics and SHCs.

Methods

This thesis is based on the Swedish Aging with Spinal Cord Injury Study (SASCIS), a population-based longitudinal cohort study of persons aged 50 years or older and at least 10 years after SCI. The SASCIS was designed to increase our knowledge of factors associated with healthy aging among people with long-term SCI.

In this thesis, parts of the baseline data collected within the SASCIS were used. This section starts with a background to describe how the SASCIS was designed, including an overview of the recruitment procedure and data collection. Thereafter follows a description of the four studies included in this thesis, the data collected, the assessment tools and statistical analyses.

Design of the Swedish Aging with Spinal Cord Injury Study

Setting and recruitment

All the participants lived in the community and were recruited through databases at the SCI Unit at Skåne University Hospital. The Unit serves a catchment area of 1.8 million people and provides primary rehabilitation for the majority of individuals with newly sustained SCI in southern Sweden.

The two main inclusion criteria for the SASCIS were: (1) age 50 years or older and (2) at least 10 years after a traumatic SCI or acquired, non-progressive non-traumatic SCI. The participants were also required to understand written and oral information given in Swedish and reside in the southern part of Sweden.

There were several reasons for focusing on persons at least 50 years old and at least 10 years post-SCI. We wanted to enroll participants with acquired SCI of all etiologies, who were in a stable phase after injury and who had started to experience the effects of aging. It has been shown that a significant loss of muscle mass starts in mid-life in the general population,[133] which is likely to be more noticeable in people with SCI. Moreover, age-related activity limitations and a decline in physical independence can occur already in the fifth decade among people with SCI.[76] Other

reasons for choosing 50 years as the lower limit for inclusion were that middle-aged people have many years ahead of them in order to benefit from developments within healthcare and society, and are more likely to participate in longitudinal follow-ups.

With the help of staff at the SCI Unit, the author of this thesis (SJ) searched databases and registers of all former patients who had been in contact with the Unit over the past four decades. At the time of recruitment (year 2011), the databases comprised 658 individuals who were still alive. Of these, 184 matched the inclusion criteria and were invited to participate. The final study sample comprised 123 (67% response rate) men and women. A flow chart of the recruitment procedure is presented in Figure 3.

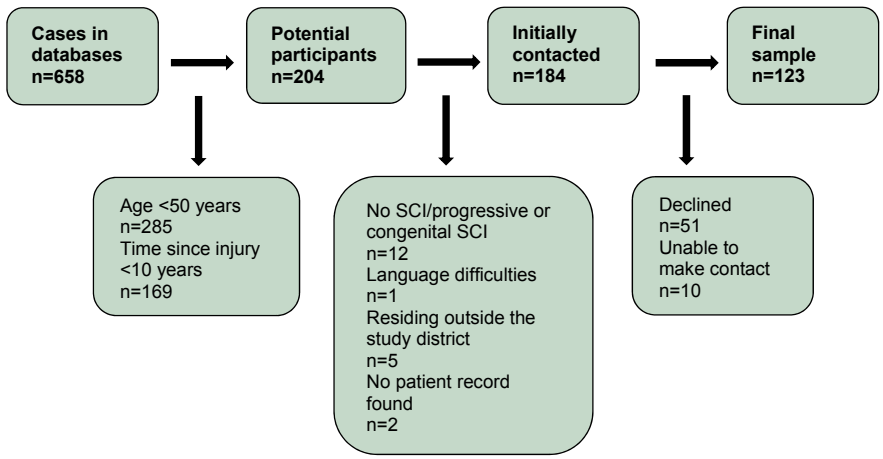

Figure 3.
Recruitment procedure of the Swedish Aging with Spinal Cord Injury Study (SASCIS).

Data collection procedure and assessment tools

Data were collected from the participants' medical records and from structured interviews and assessments during home visits. The interviews were conducted according to a study-specific questionnaire (Appendix), developed by SJ and the principal investigator of the SASCIS (Jan Lexell), and eight generic and four SCI-specific assessment tools (Table 2). The tools were chosen to cover all components of the ICF in order to ensure a holistic view of functioning, disability and health among older adults with long-term SCI.

The data collection was conducted by SJ together with a registered occupational therapist (Lizette Norin), from May 2011 to December 2012. The home visits

generally lasted for two hours and two or three participants were interviewed and assessed each day.

Table 2.

The generic and spinal cord injury-specific assessment tools used in the Swedish Aging with Spinal Cord Injury Study (SASCIS), and the relationship to the parts and components of the International Classification of Functioning, Disability and Health (ICF).

ICF Part	**Functioning and Disability**		**Contextual factors**	
ICF Component	Body functions and structures	Activity and participation	Environmental factors	Personal factors
Generic assessment tools				
Craig Hospital Inventory of Environmental Factors (CHIEF)			X	
*15-item Geriatric Depression Scale: (GDS-15)	X			
Housing Enabler (HE)	X		X	
Impact on Participation and Autonomy (IPA)		X		
Life Satisfaction Questionnaire (LiSat-11)		X		
*Satisfaction With Life Scale (SWLS)		X		
*13-item Sense of Coherence Scale (SOC-13)				X
Wheelchair User's Shoulder Pain Index (WUSPI)	X			
Spinal cord injury-specific assessment tools				
*Physical Activity Recall Assessment for People with Spinal Cord Injury (PARA-SCI)		X		
*Spinal Cord Independence Measure, third version (SCIM III)		X		
Spinal Cord Injuries Quality of Life Questionnaire (SCI QL-23)	X	X		
*Spinal Cord Lesion-related Coping Strategies Questionnaire (SCL CSQ)				X

*Assessment tools administered to collect data used in this thesis.
The GDS-15, the HE, the SOC-13, the PARA-SCI, the SCIM III, the SCI QL-23 and the SCL CSQ were included in the home interview.
The CHIEF, the IPA, the LiSat-11, the SWLS and the WUSPI were mailed to the participants prior to the home interview and were reviewed and collected during the visit.

Overview of this thesis

The four studies included in this thesis are summarized in Table 3.

Table 3.
Overview of the four studies in this thesis.

	Study I	Study II	Study III	Study IV
Aims	To present the methodology and initial results of the Swedish Aging with Spinal Cord Injury Study (SASCIS)	To describe SHCs, activity limitations and life satisfaction among older adults with long-term SCI, and to investigate how socio-demographics, injury characteristics, and SHCs are associated with their activity limitations and life satisfaction	To describe participation in LTPA among older adults with long-term SCI, and to investigate the associations with socio-demographics, injury characteristics and SHCs	To assess the presence of depressive symptoms among older adults with long-term SCI, and investigate the association with sociodemographics and injury characteristics, and to determine how potentially modifiable factors (SHCs, SOC, coping strategies, LTPA) are associated with depressive symptoms
Design	Study protocol, cross-sectional, descriptive	Cross-sectional, descriptive and analytic	Cross-sectional, descriptive and analytic	Cross-sectional, descriptive and analytic
Number of participants	123	123	119	122
Data	Overview of the data collection methods used in the SASCIS Socio-demographics and injury characteristics of the participants and the non-participants	Sociodemographics and injury characteristics SHCs Activity limitations Life satisfaction	Socio-demographics and injury characteristics SHCs LTPA	Sociodemographics and injury characteristics SHCs Depressive symptoms SOC Coping strategies LTPA
Data collection methods	Study-specific questionnaire Medical records	Study-specific questionnaire Medical records SCIM III SWLS	Study-specific questionnaire Medical records PARA-SCI	Study-specific questionnaire Medical records GDS-15 SOC-13 SCL CSQ PARA-SCI
Statistical analyses	Kruskal-Wallis test, Mann-Whitney U-test, chi-square test	Kruskal-Wallis test, Mann-Whitney U-test, chi-square test, Spearman's rank correlation coefficient, univariable and multivariable linear regression analyses (enter)	Independent-samples t-test, one-way ANOVA, hierarchical multivariable linear regression analyses	Kruskal-Wallis test, Mann-Whitney U-test, effect sizes, chi-square test, odds ratios, Spearman's rank correlation coefficient, multivariable linear regression analyses (backward elimination)

SHCs=secondary health conditions (i.e., bowel and bladder dysfunction and related problems, spasticity, pain); SCI=spinal cord injury; LTPA=leisure time physical activity; SOC=Sense of Coherence; SCIM III= Spinal Cord Independence Measure, third version; SWLS=Satisfaction With Life Scale; PARA-SCI= Physical Activity Recall Assessment for People with Spinal Cord Injury; GDS-15=15-item Geriatric Depression Scale; SOC-13=13-item Sense of Coherence Scale; SCL CSQ= Spinal Cord Lesion-related Coping Strategies Questionnaire; ANOVA= analysis of variance.

Data and assessment tools in this thesis

Sociodemographics and injury characteristics

Data on gender, chronological age, marital status, vocational situation, residential location, use of assistance, use of mobility devices, time since injury, age at injury, cause of injury and level and severity of injury (according to the AIS[1]) were collected from the participants' medical records and by the study-specific questionnaire. To enable comparisons within the study sample, three SCI severity groups were formed: (1) tetraplegia AIS A-C (n=22); (2) paraplegia AIS A-C (n=41) and (3) all AIS D (n=60).[134]

Secondary health conditions

The participants were asked about bowel and bladder function (voluntary versus non-voluntary) and the occurrence (present versus not present) of recurring bowel-related and bladder-related problems (e.g., bowel and urinary incontinence, constipation, diarrhea, urinary urgency, frequent urinary tract infections), spasticity and nociceptive and neuropathic pain during the past year. The participants rated the greatest pain intensity experienced in daily life on a 100 millimeter Visual Analog Scale (VAS) for Pain ranging from 'no pain' to 'the worst pain imaginable'. Pain intensity was categorized according to Jensen et al.[29] as mild (5-44 mm), moderate (45-74 mm) or severe (75-100 mm). Based on clinical judgement and previous research,[135] pain was dichotomized into no or mild pain versus moderate to severe pain.

Activity limitations

Data on activity limitations were collected using the Spinal Cord Independence Measure (SCIM).[136] The third version (SCIM III) used in this thesis, covers 19 tasks and the total score ranges from 0 to 100.[9] Greater scores indicate greater physical independence and, hence, less activity limitations. Cronbach's alpha, used to assess internal consistency, was in the SASCIS sample 0.91.

Depressive symptoms

Data on the presence of depressive symptoms were collected using the 15-item Geriatric Depression Scale (GDS-15),[3] consisting of 15 questions with dichotomous

responses (yes/no). The total score ranges from 0 to 15 and greater scores indicate more depressive symptoms. A score of 5 or more indicates clinically relevant depressive symptoms,[16, 17] and a score of 10 or more can be interpreted as indicative of probable depression.[16] Cronbach's alpha in the SASCIS sample was 0.77.

Sense of coherence

Data on SOC[12] were collected using the 13-item SOC scale (SOC-13).[13] The scale captures the three SOC dimensions: comprehensibility (i.e., the ability to understand the surrounding environment), manageability (i.e., the ability to manage a given situation) and meaningfulness (i.e., the ability to find a situation meaningful).[12, 137] The participants were asked to rate their agreement with 13 statements on a 7-point Likert scale. Item scores are summed with a total score ranging from 13 to 91.[138] Greater scores indicate a stronger SOC,[13] but there are no cut-off values defining a strong or weak SOC. Cronbach's alpha in the SASCIS sample was 0.84.

Coping strategies

Data on coping strategies were collected using the Spinal Cord Lesion-related Coping Strategies Questionnaire (SCL CSQ), consisting of three subscales: Acceptance, Fighting spirit, and Social reliance.[11] The participants were asked to rate their agreement with 12 statements on a 4-point Likert scale. Greater scores indicate greater use of the respective coping strategy.[11] Cronbach's alpha in the SASCIS sample was 0.74 for the Acceptance subscale, 0.39 for the Fighting spirit subscale and 0.78 for the Social reliance subscale. The internal consistency for the Fighting spirit subscale did not reach an acceptable level, and this subscale was excluded from further analyses.

Leisure time physical activity

Data on participation in LTPA were collected using the Physical Activity Recall Assessment for People with Spinal Cord Injury (PARA-SCI).[8] The PARA-SCI is a SCI-specific, self-report assessment performed according to a standardized, structured interview protocol.[139] It captures the intensity, duration, type and frequency of all physical activities (i.e., LTPA and ADL) performed during the past three days. The tool includes a SCI-specific intensity classification chart to facilitate the rating of activity intensity.[8] Only data on LTPA were used in this thesis, presented as the mean number of minutes per day of LTPA of at least mild intensity (i.e., total LTPA) and of moderate-to-heavy intensity (i.e., moderate-to-heavy

LTPA), respectively. Together with the developer,[8] we made a forward-backward translation of the tool and conducted a pilot study in the Swedish context[140] before including the PARA-SCI in the SASCIS data collection.

Life satisfaction

Data on global life satisfaction were collected using the Satisfaction With Life Scale (SWLS).[14] The participants were asked to rate their agreement with 5 statements on a 7-point Likert scale, generating a sum score ranging from 5 to 35, where a greater score corresponds to a higher level of life satisfaction. A score of 20 is considered the midpoint where the respondent is equally satisfied and dissatisfied with life.[22] The SWLS scores were categorized as: 'very high score; highly satisfied' (a score of 30-35), 'high score' (a score of 25-29), 'average score' (a score of 20-24), 'slightly below average in life satisfaction' (a score of 15-19), 'dissatisfied' (a score of 10-14), and 'extremely dissatisfied' (a score of 5-9).[141] Cronbach's alpha in the SASCIS sample was 0.86.

Data management and statistical analyses

All data were entered into the IBM SPSS Statistics for Windows (IBM Corporation, Armonk, NY, USA) and underwent a quality control process to ensure that the SASCIS database accurately represented the collected data. Imputation was used when data were missing for less than four items on the GDS-15,[142] and for one item on the SOC-13. A score for each subscale of the SCL CSQ was calculated if less than half of the items were missing, as recommended by the developers.[143] For data collected with the PARA-SCI (i.e., LTPA), two outliers (greater than the mean ±3 standard deviations (SD)) were reduced to the next lowest value in the distribution.[144] The LTPA data were positively skewed but still exhibited a large variability and range. As ranking of the data would result in lost information, the data were square root transformed.

Data were presented by means of descriptive statistics such as frequencies, mean, median, SD, minimum and maximum and interquartile range (Q_1-Q_3). The distributions of continuous data were visually inspected using histograms. As some data were skewed, non-parametric statistics were used in Studies I, II and IV. The Kruskal-Wallis test and the Mann-Whitney U-test were used to test for between-group differences and the Spearman's rank correlation coefficient to assess correlations between variables. Between-group comparisons for square root transformed LTPA data were assessed using the independent-samples t-test and

one-way analysis of variance (ANOVA) in Study III. Between-group differences in categorical data were assessed using the chi-square test.

Multivariable linear regression analyses were used to investigate associations between the dependent variables (activity limitations, depressive symptoms, participation in LTPA and life satisfaction) and possible independent variables. The independent variables were chosen based on previous research, the study aims, clinical judgement and the results of univariable regression analyses (Study II), and t-tests and ANOVAs (Study III). Table 4 gives an overview of the dependent and independent variables in Studies II-IV.

Table 4.
Overview of the dependent and independent variables in the multivariable linear regression analyses in this thesis.

	Study II	**Study III**	**Study IV**
Dependent variables	Activity limitations Life satisfaction	Leisure time physical activity	Depressive symptoms
Independent variables	Sociodemographics Injury characteristics Secondary health conditions	Sociodemographics Injury characteristics Secondary health conditions	Sociodemographics Injury characteristics Secondary health conditions Sense of coherence Coping strategies Leisure time physical activity

None of the models had residual outliers or influential cases, or was biased by multicollinearity. All residuals were uncorrelated and no residuals deviated substantially from the normal distribution. For the models with LTPA as the dependent variable (Study III), there was some evidence of heteroscedasticity as the models yielded slightly greater residuals at higher levels of LTPA. All other models exhibited evidence of homoscedasticity.

P-values less than 0.05 were considered statistically significant. Adjusted R^2 was used as a measure of explained variance in the multivariable linear regression analyses.

Ethical considerations

Striving for new knowledge must not take precedence over the rights and interests of study participants.[145] Although data were collected during time-consuming home interviews, the studies in this thesis involved no other foreseeable discomfort.

The SASCIS was approved by the Regional Ethical Review Board in Lund (No. 2010/692) and the Declaration of Helsinki for research on humans[145] was followed. A letter with information about the study and a written informed consent form was sent to all eligible participants. Those who returned a signed written informed consent to participate were contacted by telephone to receive more information about the study and an opportunity to ask questions. They were also informed about their right to withdraw from participation at any time without giving a reason. The participants chose a time and place for the interview and assessments. All collected data were handled to ensure the participants' integrity and privacy.

All participants were able to understand our questions and none of them had any major cognitive impairments. In some cases, a family member or friend was present to clarify some issues that arose due to language difficulties. This was always suggested by the participant and did not cause deviation from the study protocol.

Visits to the participants' homes required respect for their personal integrity and we made sure to create a comfortable interview situation. The home visits often lasted for more than two hours, which may have been strenuous for some participants. In the beginning of each data collection session, the procedures of the home visit and its duration were outlined. The participants were offered breaks during the interview and sometimes the participants themselves suggested a break for coffee.

Questions about depressive symptoms, psychological resources and life satisfaction sometimes gave rise to reflections and concerns. When a participant showed signs of distress or discomfort, he or she was given the opportunity to reflect upon the evoked feelings. If the participants spoke of physical or psychological complaints, they were given advice and guidance for treatment. If needed, contacts with the SCI Unit or the local healthcare center were arranged.

The overall impression was that the participants regarded participation in the SASCIS as beneficial. They were eager to share their experiences of living long-term with SCI and also requested future follow-up interviews.

Results

In this section, the results are presented in two parts: i) the descriptive findings and ii) the investigated associations.

Descriptive findings

Sociodemographics and injury characteristics

The SASCIS baseline sample included 36 women and 87 men, with a mean age of 63 years and a mean time since injury of 24 years. Figure 4 shows the age distribution among the men and the women. A total of 76% of the participants were between 50 and 69 years old.

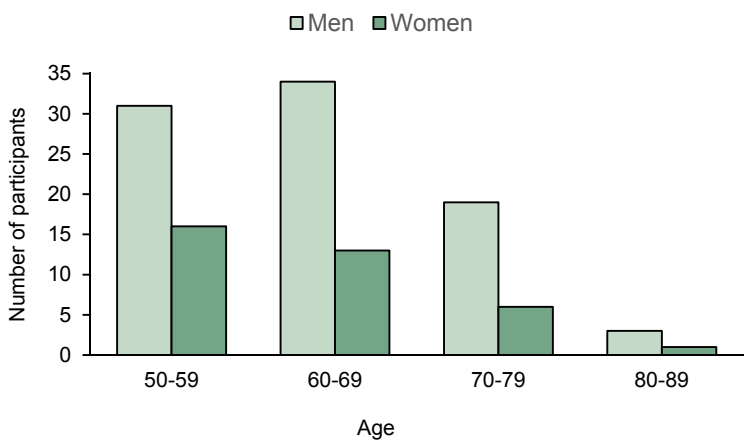

Figure 4.
Age distribution among the 36 women and 87 men in the Swedish Aging with Spinal Cord Injury Study (SASCIS).

The sociodemographics and injury characteristics of the total sample are presented in Table 5. Injury levels ranged from C1-L5, and almost one third (31%) had

sustained a complete injury. None of the participants was strictly ventilator-dependent. Paraplegia AIS D was the most common type of injury (28%). Almost two thirds (62%) had sustained a traumatic SCI; the most common cause of injury was transportation-related accidents. A large majority (88%) used mobility devices. Two thirds of the participants used some form of assistance, mostly personal (n=36; 29%) but also other forms of assistance (e.g., home-help service, help with cleaning/household/maintenance). Slightly more than half of the participants (53%) were living in a relationship and more than one third (35%) were vocationally active. Men were more likely to have sustained a traumatic SCI compared to women ($p=0.004$). Participants with a traumatic SCI were younger ($p=0.044$), had a longer time since injury ($p<0.001$) and were younger at injury ($p<0.001$), compared to those with non-traumatic SCI.

The three SCI severity groups did not differ regarding chronological age, marital status or vocational situation. Pairwise comparisons between the three SCI severity groups revealed that participants with an AIS D injury were more likely to have sustained a non-traumatic SCI, had a shorter time since injury and were older at injury (all p-values ≤ 0.013), compared to the other two groups.

Sixty-one potential participants declined to take part in the SASCIS or were unreachable (cf. Figure 3), giving a total response rate of 67%. The non-participants did not differ significantly from the study sample regarding gender, chronological age, time since injury, age at injury, cause of injury and level and severity of injury.

Table 5.

Sociodemographics and injury characteristics of older adults with long-term spinal cord injury (n=123) in the Swedish Aging with Spinal Cord Injury Study (SASCIS).

	n (%); mean ±SD; median, min-max
Gender	
Men	87 (71)
Women	36 (29)
Age (years)	63 ±9; 63, 50-89
Age at injury (years)	39 ±16; 38, 7-74
Time since injury (years)	24 ±12; 22, 10-56
Cause of injury	
Traumatic[a]	76 (62)
Non-traumatic[b]	47 (38)
Level and severity of injury	
Tetraplegia AIS A-C	22 (18)
Paraplegia AIS A-C	41 (33)
All AIS D	60 (49)
Marital status	
Married/co-habiting/partner	65 (53)
Single	58 (47)
Vocational situation	
Working full-time/part-time	43 (35)
Disability pension/old age pension	80 (65)
Residential location	
Urban	78 (63)
Rural	45 (37)
Use of assistance[c]	83 (67)
Use of mobility device indoors	
Manual wheelchair	60 (49)
Powered wheelchair/scooter	18 (15)
Walking devices	15 (12)
No mobility device	30 (24)
Use of mobility device outdoors	
Manual wheelchair	39 (32)
Powered wheelchair/scooter	51 (41)
Walking devices	18 (15)
No mobility device	15 (12)

AIS=American Spinal Injury Association (ASIA) Impairment Scale;[1] SD=standard deviation.
[a]Traffic/transportation, fall, workplace accident, diving accident, gunshot/assault/torture, other traumatic.
[b]Spinal tumor, spinal disk herniation, spinal arteriovenous malformation, spinal infarction, spinal infection.
[c]Including personal assistance, home-help service, dependent on next-of-kin/significant other, personal security alarm, help with cleaning/household/maintenance, escort, other.

Secondary health conditions

Almost half (47%) of the participants had voluntary bowel function and more than one third (37%) had voluntary voiding. CIC was the most common method for bladder emptying, used by 43% of the participants, and only 5% had an indwelling transurethral catheter.

About one third (32%) of the participants reported bowel-related problems and 44% reported bladder-related problems (Table 6). Spasticity was present in 44%. A large majority (85%) reported some type of pain and two thirds (66%) had moderate to severe pain. Participants who reported moderate to severe neuropathic pain had a shorter time since injury (p=0.028), were older at injury (p=0.019) and were less likely to be vocationally active (p=0.004) compared to those reporting no or mild neuropathic pain.

Table 6.
Secondary health conditions among older adults with long-term spinal cord injury (n=123) in the Swedish Aging with Spinal Cord Injury Study (SASCIS).

	n (%)
Bowel-related problems[a]	39 (32)
Incontinence	15 (12)
Constipation	14 (11)
Other (e.g., diarrhea, irregularity)	19 (15)
Bladder-related problems[a]	54 (44)
Incontinence	32 (26)
Urgency	17 (14)
Frequent urinary tract infections[b]	12 (10)
Other (e.g., time-consuming, bladder stones)	5 (4)
Spasticity[c]	54 (44)
Pain[d]	105 (85)
Nociceptive pain	76 (62)
Mild (VAS 5-44 mm)	27 (22)
Moderate (VAS 45-74 mm)	30 (24)
Severe (VAS 75-100 mm)	19 (15)
Neuropathic pain[e]	81 (66)
Mild (VAS 5-44 mm)	16 (13)
Moderate (VAS 45-74 mm)	28 (23)
Severe (VAS 75-100 mm)	33 (27)
Nociceptive and neuropathic pain	52 (42)

VAS=Visual Analog Scale (0-100 mm).
[a]Recurring problems during the past year. Several participants reported more than one type of problem.
[b]Recurring urinary tract infections more than 3 times per year.
[c]Recurring spasticity during the past year.
[d]Recurring pain during the past year. Pain intensity was classified according to Jensen et al.[135]
[e]Among the participants reporting neuropathic pain, one was unable to rate the pain intensity, one rated the pain intensity to 4 mm and two participants rated the pain intensity to 0 mm with analgesics.

Activity limitations

Activity limitations varied considerably among the participants, with a mean SCIM III total score of 65.2 (±24.2, median 70, Q_1-Q_3 49-84), indicating on average moderate activity limitations. Pairwise comparisons between the three SCI severity groups revealed that participants with tetraplegia AIS A-C injuries had the most activity limitations and those with AIS D injuries the least (all p-values <0.001). Activity limitations were significantly correlated with age at injury (rho=0.28; p=0.002) and time since injury (rho=–0.37, p<0.001). Participants who were younger at injury and had a longer time since injury thus exhibited more activity limitations.

Depressive symptoms and psychological resources

The participants reported on average 3.4 depressive symptoms (±2.9, median 3, Q_1-Q_3 1-5). Participants who worked and/or had a partner reported significantly fewer depressive symptoms than those who were unemployed and/or single (p<0.001 and p=0.015, respectively). A total of 35 participants (29%) exhibited clinically relevant depressive symptoms and six participants (5%) were regarded as having probable depression.

There was a considerable variation in SOC ratings. The average SOC-13 score was 71.3 (±11.8, median 73, Q_1-Q_3 66-80), indicating a strong SOC among the participants. The coping strategies Social reliance and Acceptance were used to a similar degree.

Leisure time physical activity

Participation in LTPA varied considerably but was generally low, and almost one third (29%) of the participants did not participate in any LTPA. Among the active participants, the most frequently performed activities were walking and wheeling. On average, the participants reported 34.7 minutes per day of total LTPA (±41.5, median 15.0, Q_1-Q_3 0.0-57.0), ranging from 0 to 171.7. The average amount of moderate-to-heavy LTPA was 22.5 minutes per day (±35.1, median 5.0, Q_1-Q_3 0.0-30.0), ranging from 0 to 140.0. The 63 participants who were active at a moderate-to-heavy intensity level reported on average 42.5 minutes per day (±38.5, median 30.0, Q_1-Q_3 15.0-63.3), ranging from 0.5 to 140.0 (Figure 5).

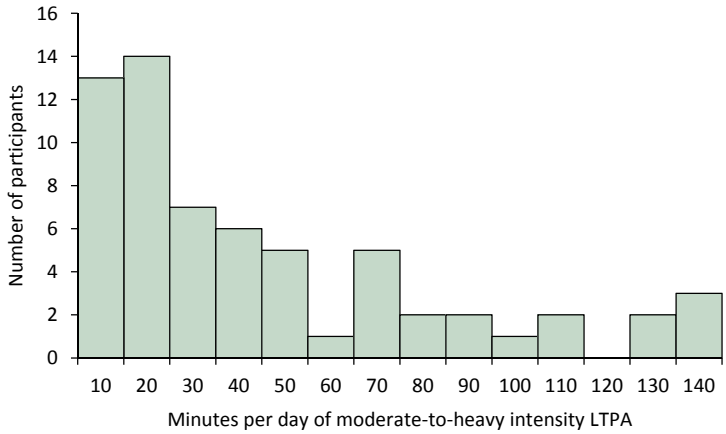

Figure 5.
Distribution of the average minutes per day of moderate-to-heavy intensity leisure time physical activity among older adults with long-term spinal cord injury active at this intensity level (n=63), in the Swedish Aging with Spinal Cord Injury Study (SASCIS).

Life satisfaction

Life satisfaction was rated just above the midpoint between satisfied and dissatisfied with life, i.e., mean SWLS total score 20.7 (±7.1, median 21, Q_1-Q_3 14-27). One third of the participants were satisfied (21%) or highly satisfied (13%) with life. One fourth were dissatisfied (21%) or extremely dissatisfied (5%) with life. Participants who worked and/or had a partner reported a significantly higher level of life satisfaction than those who were unemployed and/or single (p-values <0.001).

Investigating associations

Activity limitations

In Table 7, the multivariable linear regression analysis investigating associations between activity limitations (dependent variable) and sociodemographics, injury characteristics and SHCs is presented. The independent variables explained 68% of the variance in activity limitations, with a higher level and more severe SCI (based on the AIS) and spasticity being significantly associated with more activity limitations. Level and severity of injury was the strongest contributor to the explained variance. As can be seen in Table 7, a tetraplegia AIS A-C injury is

associated with almost 50 points less on the SCIM III compared to an AIS D injury, given that the other independent variables are held constant.

Table 7.
Multivariable linear regression analysis with activity limitations (assessed with the Spinal Cord Independence Measure, third version; SCIM III) as the dependent variable (n=123), in the Swedish Aging with Spinal Cord Injury Study (SASCIS).

Independent variables[a]	B	95% confidence interval for B	β	p-value
Tetraplegia AIS A-C[b]	-49.28	-56.74, -41.82	-0.79	<0.001
Paraplegia AIS A-C[b]	-17.37	-23.49, -11.25	-0.34	<0.001
Time since injury (in 10 year intervals)	-1.28	-3.61, 1.06	-0.06	0.28
Non-traumatic injury	2.46	-3.38, 8.31	0.05	0.41
Spasticity	-9.47	-14.53, -4.41	-0.20	<0.001
Adjusted R^2		0.68		

AIS=American Spinal Injury Association (ASIA) Impairment Scale;[1] B=unstandardized regression coefficient; β=standardized regression coefficient.
Greater SCIM III[9] scores indicate less overall activity limitations (range 0-100).
[a]Independent variables with p<0.30 in univariable regression analyses with the SCIM III total score as the dependent variable and gender, age, level and severity of injury, time since injury, cause of injury, spasticity and nociceptive and neuropathic pain as independent variables.
[b]Reference category: All AIS D.

Depressive symptoms

The multivariable linear regression analysis investigating associations between the number of depressive symptoms (dependent variable) and sociodemographics and injury characteristics explained 13% of the variance. A tetraplegia and paraplegia AIS A-C injury (compared to an AIS D injury), a non-traumatic injury and an active vocational situation were significantly associated with fewer depressive symptoms. The use of a powered wheelchair/scooter outdoors (compared to use of walking devices/no mobility device) was significantly associated with more depressive symptoms.

In Table 8, the multivariable linear regression analysis investigating associations between the number of depressive symptoms (dependent variable) and SHCs, SOC, coping strategies and LTPA is presented. The independent variables explained 53% of the variance in the number of depressive symptoms. A stronger SOC, greater use of the coping strategy Acceptance and more minutes per day of LTPA were significantly associated with fewer depressive symptoms, whereas moderate to severe neuropathic pain was significantly associated with more depressive symptoms. SOC was by far the strongest contributing factor to the explained variance in the number of depressive symptoms.

Table 8.

Multivariable linear regression analysis with the number of depressive symptoms (assessed with the 15-item Geriatric Depression Scale; GDS-15) as the dependent variable (n=118[a]), in the Swedish Aging with Spinal Cord Injury Study (SASCIS).

Independent variables	B	95% confidence interval for B	β	p-value
Moderate to severe neuropathic pain[b]	0.85	0.12, 1.58	0.15	0.023
Sense of coherence[c]	-0.14	-0.17, -0.10	-0.54	<0.001
Coping; Acceptance[d]	-1.08	-1.58, -0.57	-0.29	<0.001
Leisure time physical activity[e]	-0.01	-0.02, -0.004	-0.18	0.006
Adjusted R^2		0.53		

B=unstandardized regression coefficient; β=standardized regression coefficient.
Greater GDS-15[3] scores indicate more depressive symptoms (range 0-15).
The regression model was obtained from an initial model with secondary health conditions (bowel-related and bladder-related problems, spasticity and neuropathic and nociceptive pain), sense of coherence, coping strategies and leisure time physical activity as independent variables, using a multivariable linear regression analysis with backward elimination.
[a]A total of 122 SASCIS participants completed the GDS-15. Three of those did not complete the Physical Activity Recall Assessment for People with Spinal Cord Injury (PARA-SCI), and one was unable to rate the intensity of neuropathic pain.
[b]Reference category: No or mild neuropathic pain.
[c]13-item Sense of Coherence Scale (SOC-13).[13] Greater scores indicate a stronger SOC (range 13-91).
[d]Spinal Cord Lesion Related Coping Strategies Questionnaire (SCL CSQ).[11] Greater scores indicate greater use of the corresponding coping strategy (range 1-4).
[e]PARA-SCI,[8] calculated as minutes per day of total leisure time physical activity.

When the significant independent variables from the two multivariable linear regression models investigating factors associated with depressive symptoms were combined in a final multivariable analysis, the resulting model was identical to that in Table 8. That is, adding sociodemographics and injury characteristics to the model did not change the association between depressive symptoms and SOC, the coping strategy Acceptance, participation in LTPA and neuropathic pain.

Leisure time physical activity

In Table 9, the hierarchical multivariable linear regression analyses investigating associations between the average minutes per day of total LTPA (dependent variable) and sociodemographics, injury characteristics and SHCs are presented. The final model explained 11% of the variance. Older age and outdoor wheelchair use (compared to use of walking devices/no mobility device) were significantly associated with less participation in LTPA. The use of a powered mobility device exhibited the strongest association with fewer minutes per day of total LTPA.

Table 9.

Hierarchical multivariable linear regression analyses with the average minutes per day of total leisure time physical activity (assessed with the Physical Activity Recall Assessment for People with Spinal Cord Injury; PARA-SCI) as the dependent variable (n=118[a]), in the Swedish Aging with Spinal Cord Injury Study (SASCIS).

Model	Independent variables	B	95% confidence interval for B	β	p-value	Adjusted R^2; p-value for the model
1	Age	-0.39	-1.27, 0.50	-0.08	0.39	0.004
	Female gender	-11.14	-27.89, 5.61	-0.12	0.19	p=0.29
2	Age	-0.57	-1.48, 0.35	-0.12	0.22	0.002
	Female gender	-11.92	-29.17, 5.33	-0.13	0.17	p=0.39
	Time since injury	-0.22	-0.94, 0.51	-0.06	0.56	
	Tetraplegia AIS A-C[b]	-14.85	-37.21, 7.52	-0.14	0.19	
	Paraplegia AIS A-C[b]	-2.66	-20.94, 15.62	-0.03	0.77	
3	Age	-0.61	-1.5, 0.28	-0.13	0.18	0.07
	Female gender	-10.74	-27.47, 5.99	-0.12	0.21	p=0.049
	Time since injury	0.08	-0.69, 0.85	0.02	0.83	
	Tetraplegia AIS A-C[b]	1.48	-22.64, 25.60	0.01	0.90	
	Paraplegia AIS A-C[b]	12.90	-8.51, 34.29	0.15	0.24	
	Manual wheelchair[c]	-32.61	-59.13, -6.09	-0.37	0.016	
	Powered wheelchair/scooter[c]	-34.04	-57.63, -10.46	-0.40	0.005	
	Secondary health conditions[d]	-2.19	-7.92, 3.54	-0.07	0.45	
4	Age	-1.03	-2.02, -0.045	-0.21	0.041	0.11
	Female gender	-11.88	-28.34, 4.58	-0.13	0.16	p=0.014
	Time since injury	0.10	-0.65, 0.85	0.03	0.80	
	Tetraplegia AIS A-C[b]	0.73	-22.93, 24.38	0.01	0.95	
	Paraplegia AIS A-C[b]	16.55	-4.72, 37.82	0.19	0.13	
	Manual wheelchair[c]	-33.17	-59.17, -7.16	-0.37	0.013	
	Powered wheelchair/scooter[c]	-38.69	-62.08, -15.29	-0.46	0.001	
	Secondary health conditions[d]	-3.18	-8.90, 2.53	-0.11	0.27	
	Urban residence	15.06	-0.47, 30.60	0.18	0.057	
	Working full-time/part-time	-17.04	-35.23, 1.15	-0.20	0.066	

AIS=American Spinal Injury Association (ASIA) Impairment Scale,[1] B=unstandardized regression coefficient; β=standardized regression coefficient.

[a]A total of 119 SASCIS participants completed the PARA-SCI. One participant reporting 3-5 secondary health conditions was excluded from the regression analyses as the exact number of secondary health conditions was unknown.

[b]Reference category: All AIS D.

[c]Primary mode of mobility for longer distances outdoors. Reference category: Walking devices/no mobility device.

[d]Occurrence (number, 0-5) of bowel-related and bladder-related problems, spasticity and moderate to severe nociceptive and neuropathic pain.

Hierarchical multivariable linear regression analyses were computed also for moderate-to-heavy LTPA. The final regression model investigating associations between the average minutes per day of moderate-to-heavy LTPA (dependent variable) and sociodemographics, injury characteristics and SHCs, explained 13% of the variance. Being a woman, using a wheelchair and working were significantly associated with less participation in moderate-to-heavy LTPA. Also here, the use of a powered mobility device exhibited the strongest association with fewer minutes per day of LTPA.

Life satisfaction

In Table 10, the multivariable linear regression analysis investigating associations between life satisfaction (dependent variable) and sociodemographics, injury characteristics and SHCs is presented. The independent variables explained 38% of the variance in life satisfaction. Four of the investigated independent variables were significantly associated with a higher level of life satisfaction: partner relationship, an active vocational situation, voluntary voiding and a paraplegia AIS A-C injury (compared to a tetraplegia AIS A-C and an AIS D injury). Having a partner was the strongest contributor to a high level of life satisfaction.

Table 10.

Multivariable linear regression analysis with life satisfaction (assessed with the Satisfaction With Life Scale; SWLS) as the dependent variable (n=111[a]), in the Swedish Aging with Spinal Cord Injury Study (SASCIS).

Independent variables[b]	B	95% confidence interval for B	β	p-value
Paraplegia AIS A-C[c]	3.43	0.77, 6.09	0.23	0.012
Non-traumatic injury	2.09	-0.43, 4.61	0.14	0.10
Having a partner	6.00	3.75, 8.25	0.42	<0.001
Working full-time/part-time	3.91	1.51, 6.31	0.26	0.002
Voluntary bowel function	0.31	-2.35, 2.98	0.02	0.82
Bowel-related problems	0.64	-2.01, 3.29	0.04	0.63
Voluntary voiding	4.21	1.37, 7.04	0.29	0.004
Bladder-related problems	-2.35	-4.73, 0.03	-0.16	0.053
Moderate to severe neuropathic pain[d]	-1.23	-3.55, 1.09	-0.09	0.30
Adjusted R^2		0.38		

AIS=American Spinal Injury Association (ASIA) Impairment Scale;[1] B=unstandardized regression coefficient; β=standardized regression coefficient.
Greater SWLS[14] scores indicate a higher level of life satisfaction (range 5-35).
[a]A total of 111 SASCIS participants completed the SWLS.
[b]Independent variables with p<0.30 in univariable regression analyses with the SWLS total score as the dependent variable and gender, age, marital status, vocational situation, level and severity of injury, time since injury, cause of injury, bowel and bladder function and related problems, spasticity and nociceptive and neuropathic pain as independent variables.
[c]Reference category: Tetraplegia AIS A-C and all AIS D.
[d]Reference category: No or mild neuropathic pain.

Discussion

The studies in this thesis were conducted to describe and understand aspects of the life situation of older adults with long-term SCI in southern Sweden. Overall, the results are positive and show that this population has some strategies and characteristics that may support healthy aging. They exhibit a relatively high level of physical independence, a low presence of probable depression, a strong SOC and are generally satisfied with their lives. However, the high occurrence of pain and the low participation in LTPA are cause for concern.

An illustration of factors associated with the participants' activity limitations, depressive symptoms, participation in LTPA and life satisfaction is presented in Figure 6. The results are depicted in relation to the components of the ICF, to show the conceptual and complex interrelationship between the investigated aspects of living into older age with long-term SCI. The significant associations identified indicate the importance of injury characteristics for activity limitations, SOC for depressive symptoms, use of mobility device for participation in LTPA and partner relationships for life satisfaction, although no causal conclusions can be drawn due to the cross-sectional study design.

Personal and environmental factors exhibit the strongest associations with depressive symptoms, participation in LTPA and life satisfaction. Impairments caused by the SCI are associated with activity limitations, while not being as strongly related to depressive symptoms or life satisfaction, and not being associated with participation in LTPA. The amount of variance explained in activity limitations, depressive symptoms and life satisfaction indicates that we have identified some factors of relevance for these aspects of living into older age with long-term SCI. Conversely, the results clearly demonstrate the need for more research regarding participation in LTPA and associated factors.

Summarizing our understanding of the life situation of older adults with long-term SCI in southern Sweden thus far, this thesis provides an empirically grounded starting point for future research. It also presents some guidance on aspects to consider in clinical follow-up. One reason for the overall positive results may be that the lifelong SCI rehabilitation programs are valuable sources of support. The variety of factors associated with activity limitations, depressive symptoms, participation in LTPA and life satisfaction illustrate the importance of gathering the expertise of different rehabilitation professionals to enable healthy aging many

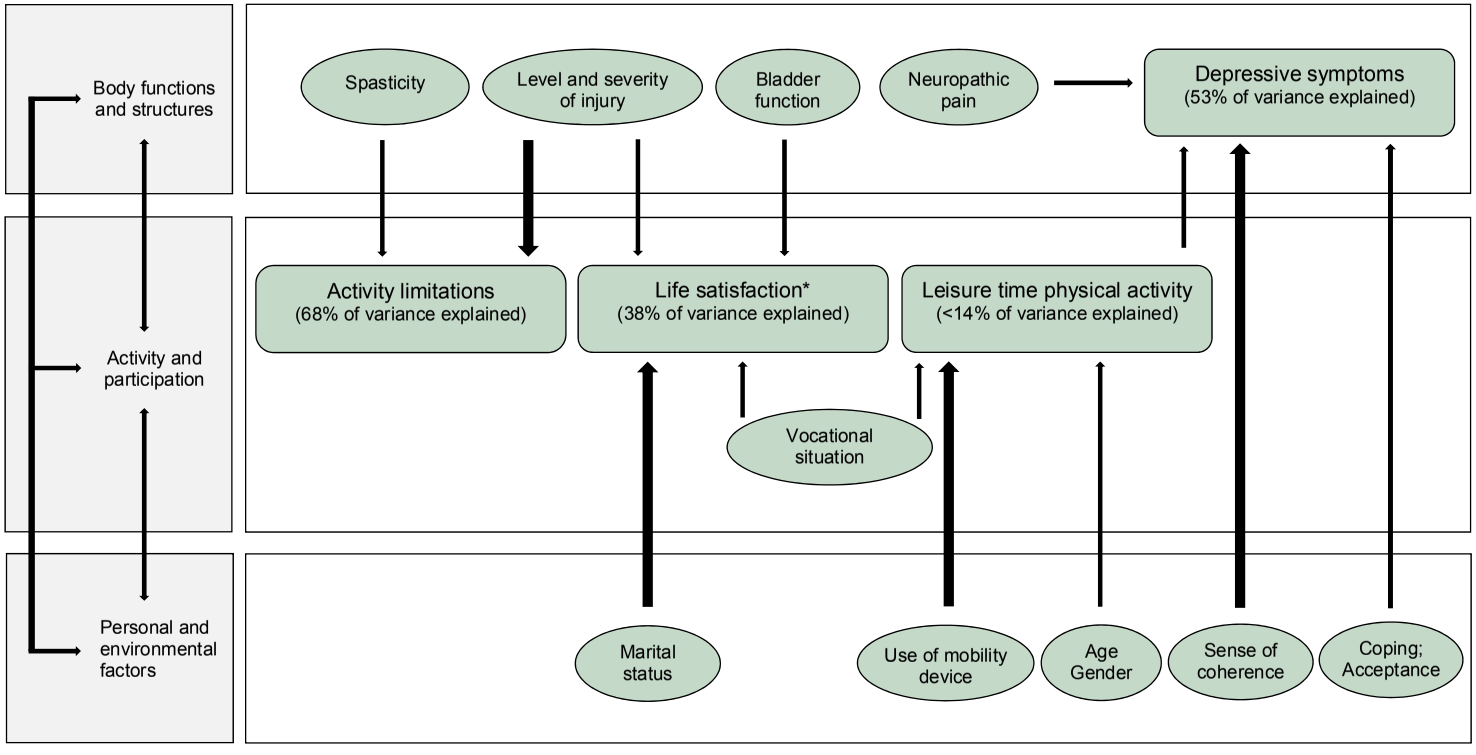

Figure 6.
Illustration of factors associated with activity limitations, depressive symptoms, participation in leisure time physical activity and life satisfaction among older adults with long-term spinal cord injury in the Swedish Aging with Spinal Cord Injury Study (SASCIS). The results are depicted in relation to the components of the International Classification of Functioning, Disability and Health (ICF). The broad arrows represent the strongest explanatory factors. Causal relationships between variables cannot be established due to the cross-sectional study design.
*Items in the Satisfaction With Life Scale represent facets of the ICF component participation.[146]

years after SCI. Thus, long-term follow-up programs need resources to maintain their services and thereby accommodate the growing number of older adults with long-term SCI in times of financial constraints within the healthcare sector. Well-coordinated follow-up routines at a SCI Unit will most likely be financially beneficial in the long-term perspective.

Sociodemographics and injury characteristics

Our sample represents two thirds of the population of older adults with long-term SCI in southern Sweden. As no significant differences were found between the participants and the non-participants, the SASCIS sample is most likely representative of the target population.

There was, as expected, a majority of men in our study sample. Traumatic injuries were more common than non-traumatic injuries, almost half of the participants had an AIS D injury and thoracic and lumbar injuries were more common than cervical injuries. With regard to these aspects, the SASCIS sample does not differ from newly injured individuals in Sweden.[33]

The most common traumatic etiology in the SASCIS sample was transportation-related accidents, whereas fall-related injuries is the most common cause of newly sustained traumatic SCI in Sweden.[33] This decrease in transportation-related injuries could reflect an improvement of road traffic safety as well as a greater safety awareness related to transportation. The increase in fall-related injuries corresponds to the recent trend that more people over the age of 65 years sustain SCI.[30] Participants with non-traumatic SCI were older at injury, which relates to more age-related diseases, such as spinal tumors, degenerative disorders and vascular accidents.

None of our participants was strictly ventilator-dependent, which could reflect the increased mortality rate among those with high level and more severe injuries. All participants lived in their own homes, and many used some form of assistance and/or mobility devices. One can speculate that the support provided by the Swedish welfare system has positively influenced the living conditions for the SASCIS participants. Almost one third of them needed personal assistance. However, by the age of 65, hours for personal assistance will not be extended and new applications for assistance will not be granted.[62] Our participants may then be faced with less support than they need which could limit their ability to achieve healthy aging on equal terms with others of the same age.[64, 80] Age-related changes in opportunities for societal services and support were not examined in this thesis, but is an area for future research with implications for many segments of the aging population.

Although SCI can have a negative impact on partner relationships,[30] more than half of the SASCIS participants had a partner and the proportions of participants living in a relationship did not differ across the three SCI severity groups. Early retirement was not as frequent as might be expected as more than half of those of working age (i.e., at or below 65 years of age) were vocationally active. An active vocational situation was associated with several aspects of living into older age with long-term SCI. To investigate how the participants' life situation changes when a greater proportion of them transition into retirement age is an interesting topic for future longitudinal studies.

Secondary health conditions

Bowel-related and bladder-related problems and spasticity appear to be less common among older adults with long-term SCI in southern Sweden than in other SCI samples. Previous research has reported these SHCs to occur among 60-70% of the study participants.[82, 96, 147] One reason for the lower occurrence in the SASCIS sample may be that people living with SCI for many years have learnt to manage such impairments. Another reason may be that our participants receive appropriate guidance and treatment regarding bowel and bladder management and spasticity. The common use of CIC and the low frequency of indwelling transurethral catheters further support this statement. Thirdly, it may be that these SHCs in fact are reduced with age in this group.

Although pain was very common in our sample, it was not associated with activity limitations, participation in LTPA or life satisfaction. This could indicate an adaptation to pain over time, or that pain does not interfere to a high degree with these aspects of life. There is often a discrepancy between the occurrence of pain and the proportion of people who report pain to be a problem.[83] The results may thus have been somewhat different if only problematic pain had been registered. Nevertheless, participants reporting moderate to severe neuropathic pain were less likely to be vocationally active, and neuropathic pain was associated with depressive symptoms. Consequently, there is a need for a more comprehensive understanding of pain in this population, where the impact of pain in everyday life and pain management strategies are of particular interest. Paying attention to pain is warranted in the clinical setting to determine whether our results represent unmet needs for intervention.

Understanding and mitigating activity limitations

The finding that our participants had moderate activity limitations, assessed as physical independence, was not unexpected given that almost half of them had an AIS D injury. Indeed, a higher level and more severe injury exhibited the strongest association with more activity limitations (cf. Figure 6). The association with spasticity is supported by previous research[82, 85] and clinical experience, and indicates that spasticity should be considered to support independence in daily activities. Although the level and severity of injury was the strongest explanatory factor for activity limitations, measures to refine transferring techniques and provide additional or different types of assistive devices could be beneficial for physical independence.[40]

The lack of an association between chronological age and activity limitations was somewhat surprising. Older age has been associated with more activity limitations and a need for more physical assistance among people with SCI.[42, 76, 148] The relatively narrow age range in the SASCIS sample could explain why this association was not found. Longitudinal studies are therefore needed to determine the effects of aging on activity limitations, and whether the level and severity of injury moderate this association. The lower age-limit for inclusion in the SASCIS (i.e., 50 years of age) is a particular advantage in this aspect, allowing for several assessments of changes in functioning and disability over time. As to clinical follow-up, periodical team-based reassessments of ADL performance is required to mitigate the anticipated decline in physical independence among older adults with long-term SCI.[40, 64]

Understanding and reducing depressive symptoms

Probable depression appears to be less common among older adults with long-term SCI in southern Sweden than in other SCI samples (i.e., 5% versus 9-25%)[105, 110, 149, 150] and comparable to the occurrence of major depression among older adults in general (i.e., 1-5%).[151] However, clinically relevant depressive symptoms are not uncommon and more frequent than in the non-injured older population (i.e., 29% versus 8-16%).[109, 152, 153] Depressive symptoms are often under-recognized among older adults in general.[149] Of particular concern for individuals with SCI is the persistence and inadequate treatment of depressive symptoms.[110, 154] Consequently, a routine evaluation of depressive symptoms among older adults with long-term SCI would identify those at risk of developing depression and enable early intervention.

The finding that both SOC and the coping strategy Acceptance were associated with fewer depressive symptoms (cf. Figure 6) is well-recognized.[107, 108, 155, 156] It can be argued that assessments of SOC and mental health are two ways of measuring the same phenomenon.[157] People with a limited ability to understand and manage external strains would inevitably develop symptoms of depression. In this thesis, SOC was the strongest explanatory factor for depressive symptoms. Still, a considerable amount of variance was left unexplained, which indicates that there are other factors associated with depressive symptoms among older adults with long-term SCI. Thus, SOC appears to be important for mental health but not a synonymous concept.[156]

Our participants rated their SOC somewhat higher than in previous studies of people with SCI,[138] other neurological conditions,[158, 159] and comparable to older adults in the general Swedish population.[160] Although originally proposed to be a stable construct,[12] SOC can increase with age[137, 160] and the stability of SOC relies on the absence of radical and lasting changes in a person's life situation.[155] The strong SOC and the low occurrence of probable depression among our participants may reflect positive psychological changes occurring after injury[161] and with increasing age.

SOC can be regarded as a coping resource,[108] where a strong SOC increases the likelihood of selecting appropriate coping strategies to deal with a specific problem.[12] Living with SCI for many years means constantly being confronted with new challenges that require an ongoing adjustment process, and our participants seem to be well adjusted to their long-term SCI. Rehabilitation that empowers people to mobilize and reflect upon their available resources in stressful life events could be used to strengthen SOC.[162] This could facilitate future adjustment processes and possibly reduce the likelihood of developing depression.

Neuropathic pain was, somewhat surprisingly, the only SHC significantly associated with depressive symptoms. It may be that other SHCs are more manageable than neuropathic pain, that the participants have found strategies to limit their impact, or that they are not of any greater importance for mood. The relationship between pain and depression is likely to be bidirectional where pain contributes to depressed mood, which in turn aggravates pain.[163] The findings in this thesis support the potential benefits of multimodal pain management programs as part of the long-term management of SCI.[164]

The well-known relationship between physical activity and depressive symptoms in different populations[20, 110, 117, 118, 165] holds true also for older adults with long-term SCI. The association could work both ways; that is, depressive symptoms make people reluctant to participate in LTPA and low participation in LTPA contributes to depressive symptoms. Breaking this vicious cycle by encouraging participation in LTPA has few side effects but many health benefits. Exercise has in fact shown effects similar to those of pharmacological and psychological treatment in reducing

depressive symptoms.[165, 166] Further studies are needed to investigate whether interventions to increase participation in LTPA among older adults with long-term SCI can have positive effects on mood.

Understanding and promoting leisure time physical activity

It is a concern that half of the SASCIS participants performed less than 5 minutes of moderate-to-heavy intensity LTPA per day, as this level of intensity is required to reach fitness benefits after SCI.[114-116] Moreover, almost one third did not participate in any LTPA whatsoever. In comparison, 18% of non-injured Swedish adults above the age of 65 report a sedentary lifestyle.[167] It is reassuring though, that our results also show that it is possible to maintain a physically active lifestyle in older age many years after SCI (cf. Figure 5).

Older age, powered wheelchair use, pain, environmental barriers and lack of motivation and financial resources are factors identified as related to less participation in physical activity after SCI.[120, 168-170] This thesis has contributed with some knowledge in this area regarding older adults with long-term injury, indicating that clinicians should be perceptive to the unique needs of wheelchair users, older individuals, women and those who are vocationally active when evaluating and promoting participation in LTPA (cf. Figure 6).

It is noteworthy that participants using manual wheelchairs performed less LTPA than those using walking devices or no mobility device, as this finding contrasts previous research in younger SCI populations.[119, 120] Our results thereby indicate that there are specific barriers to participation in LTPA among older adults with long-term SCI who use manual wheelchairs. This may be attributed to poor wheelchair skills among older persons with SCI,[171] which emphasizes the need to assess wheelchair skills and wheelchair fitting in the clinical setting. There may also be specific environmental barriers influencing participation in LTPA in this group. More research is needed to elucidate the reasons behind this novel finding.

It is actually encouraging that sociodemographics, injury characteristics and SHCs explained less than 14% of the variance in LTPA participation. The reason is that most of the sociodemographic and injury-related variables are not modifiable by intervention. Future research should aim to identify modifiable factors associated with participation in LTPA among older adults with long-term SCI, and use this knowledge to develop specific targets for lifestyle interventions.

The results indicate that an urgent health promotion strategy to consider in the long-term management of SCI is to encourage a physically active lifestyle. Peers are

important as knowledge translators and motivators to participation in LTPA,[172] and should preferably be included in such strategies. It is important to convey the benefits of physical activity, provide evidence-based information on how to reach these benefits and introduce enjoyable activities to successfully promote participation in LTPA.[173] SCI-specific physical activity guidelines are available in Swedish and can be used in clinical practice.[114] Wheeling and walking were common activities in the SASCIS sample, but the results do not reveal if these were pleasurable activities or merely the ones closest at hand. Knowledge of preferred activities could guide clinicians and peer mentors to facilitate activities that meet the abilities and interests of older adults with long-term SCI. Telephone counseling and peer-mediated home-based strength-training programs have proven to increase participation in LTPA after SCI,[174, 175] but none of these studies focused specifically on older adults with long-term injury. Health promotion with regard to an active lifestyle is an area for future research that could potentially have a large impact on health and well-being in this population.

Understanding and increasing life satisfaction

The average rating of life satisfaction among the participants implies that older adults with long-term SCI are generally satisfied with their lives, although there are some areas where they would very much like to see an improvement.[141] However, their life satisfaction is lower than in general population samples[122] and 5% are extremely dissatisfied with life. These individuals need to be identified during clinical follow-up and provided with adequate counseling. During informal conversations, some participants expressed an unmet need to meet others in the same situation. This emphasizes the need to integrate community peer-based programs in the long-term management and rehabilitation.[54] Peer interaction can be of great importance throughout the lifespan for people with SCI,[54, 176] and has the potential for supporting healthy aging and life satisfaction.

Previous research has also shown that people who have lived with SCI for many years report rather high levels of life satisfaction.[124, 177] This may be a result of the fact that those who are better adjusted and more satisfied with life take part in follow-ups.[55, 178] Another potential explanation is that priorities, expectations and standards have shifted after the injury.[179] One of our participants made this very clear when she answered the SWLS item “In most ways my life is close to my ideal”. She said: “I completely agree, it could not be better considering my situation, which is the only situation I can refer to.” The overall positive life situations of the SASCIS participants somewhat contradict the still occurring misconception that a long-term

physical disability is incompatible with favorable living conditions, and that people with physical disabilities are dependent, passive and incapable.[30]

The findings that having a partner and being vocationally active were significantly associated with a higher level of life satisfaction (cf. Figure 6) is well in line with previous studies.[57, 81, 180-182] It is reasonable to believe that these associations reflect more than the positive effects of a partner relationship and employment per se. Both a partner relationship and employment can entail a sense of belonging and being needed, and be associated with financial security and opportunities for social support.[56, 105, 183] Indeed, social support has consistently been associated with higher levels of life satisfaction after SCI.[105] This may be explained by the association between social support and perceived problems in participation,[184] which in turn are strongly related to life satisfaction.[185] Thus, the results from this thesis and previous findings suggest that the social context and meaningful activities are of importance for satisfaction with life many years after SCI.

Given the broad construct of life satisfaction, the amount of variance explained (38%) can be considered rather high. Nevertheless, several other factors are worth considering. Previous research has shown that mental health, psychological resources and physical activity are related to life satisfaction in people with SCI and other neurological conditions.[107, 118, 128, 158, 159, 186] Examining the interaction between depressive symptoms, the associated factors (cf. Figure 6), and life satisfaction is an interesting topic for future studies. Such research might identify targets for interventions to increase life satisfaction among older adults with long-term SCI.

Methodological considerations, strengths and limitations

Great efforts were made to recruit a large and representative study sample. It is possible, despite these efforts, that those with better health, stronger psychological resources, and a satisfactory life situation were more likely to participate. Nevertheless, as the 123 participants did not differ significantly from the non-participants regarding sociodemographics and injury characteristics, the sample is likely to be representative of older adults with long-term SCI in southern Sweden.

The home interviews facilitated participation in the SASCIS, as some participants were unable to easily leave their homes. The author of this thesis performed all the interviews according to a detailed study protocol, which ensured uniformity and minimized missing data. The interviews provided first-hand insights into the everyday life of the participants and opened up for recruitment to future studies.

The assessment tools in the SASCIS were chosen based on an extensive literature search and the researchers' combined experience in rehabilitation medicine and

gerontology research. Together, the tools cover all parts and components of the ICF, and the use of the ICF framework makes the results transferrable to clinical practice. However, all items in a tool may not be readily incorporated into the framework. For example, life satisfaction is not defined in the ICF, but assessment tools in this area can be related to the participation component (i.e., involvement in a life situation),[146] as well as a broader subjective judgement upon the current life situation.[22]

The use of both generic and SCI-specific, internationally established assessment tools with robust psychometric properties[3, 8, 9, 11, 13, 122, 137, 187, 188] strengthens this thesis. Our Swedish version of the PARA-SCI was tested for usability in a Swedish context,[140] and all the assessment tools exhibited satisfactory internal consistency (i.e., Cronbach's alpha).[189] No other assessments of reliability or validity were made so further studies of the psychometric properties of the assessment tools in the SASCIS sample may therefore be warranted.

Regarding SHCs, pain intensity may have been overestimated as the greatest pain intensity experienced in everyday life was recorded. Spasticity was not physically examined but based on self-reports. We did not take into account the frequency, duration or perceived impact of the SHCs and may therefore not have been able to identify those truly restricted by these conditions.

The PARA-SCI was chosen as it was designed specifically for people with SCI and has been used in large studies and interventions.[168] As a self-report assessment, it is susceptible to recall and response bias, as well as overestimation and underestimation of participation in LTPA in comparison to objective measures.[190] Despite these limitations, the PARA-SCI was recently suggested as the most suitable self-report measure to quantify participation in physical activity among people with physical disabilities.[191]

Regarding the GDS-15, different cut-offs for identifying and classifying depressive symptoms can be found in the literature. This limits the ability to fully compare our results to previous research, and no studies were found where the GDS-15 had been used in SCI samples. The GDS-15 was still considered suitable for the SASCIS as it was developed for older adults and provides opportunities for comparison with general population samples in southern Sweden.[152] In addition, it does not contain items related to somatic symptoms of depression, which may overlap with symptoms related to SCI and aging.

The cross-sectional study design does not permit any conclusions regarding causality of the associations investigated, nor does it provide knowledge of the aging process per se. There are also much likely additional factors associated with activity limitations, depressive symptoms, participation in LTPA and life satisfaction that were not investigated in this thesis.

Conclusions

This thesis has provided new knowledge about the life situation of older adults with long-term SCI in southern Sweden.

- The 123 individuals in the SASCIS constitute a heterogeneous group with a large variation in neurological impairments, need for assistance and use of mobility devices. Despite a long-term neurological injury, these men and women exhibit a relatively high level of physical independence, a low presence of probable depression, a strong SOC and are generally satisfied with their lives.
- Bowel-related and bladder-related problems and spasticity are less common than reported in previous SCI studies, and are not associated with depressive symptoms, participation in LTPA or life satisfaction.
- Pain, both nociceptive and neuropathic, is common but not associated with physical independence, participation in LTPA or life satisfaction.
- The level and severity of injury and spasticity are important for the ability to perform daily activities, regardless of chronological age.
- Clinically relevant depressive symptoms are not uncommon. The identified explanatory factors for depressive symptoms support the contention that psychological resources, pain and physical activity are associated with mental health. In particular, the ability to understand and manage external strains, and to stay motivated when they occur, is strongly related to fewer depressive symptoms.
- Many do not reach the amount or intensity of LTPA to achieve fitness benefits. The weak association with sociodemographics and injury characteristics suggests that more research is needed to identify modifiable factors that could enhance participation in LTPA.
- The commonly identified associations between a high level of life satisfaction and a partner relationship, as well as an active vocational situation, hold true also for older adults with long-term SCI.

Clinical implications

The knowledge generated in this thesis can be used to inform rehabilitation planning and provide routines for follow-up.

- Bowel-related and bladder-related problems and spasticity may not be of specific concern among older adults with long-term SCI. However, strategies to minimize the occurrence of these SHCs should not be overlooked, and reduced spasticity may have a positive effect on physical independence.
- Pain and depressive symptoms should be routinely evaluated. Paying attention to depressive symptoms is warranted in individuals who exhibit a weak SOC, a low ability to use the coping strategy Acceptance, and among those who seek consultation for neuropathic pain.
- Measures that strengthen the ability to understand and confront life stressors, promote acceptance of the injury, provide adequate pain management and encourage participation in LTPA may support mental health.
- Participation in LTPA should be routinely assessed and encouraged. Wheelchair users, older individuals, women and those who are vocationally active may require special attention in much-needed health promotion strategies that focus on an active lifestyle.
- Facilitating social interaction and participation in meaningful activities may support high levels of life satisfaction.

Future perspectives

The follow-up data collection of the SASCIS is now ongoing and will enable us to explore changes over time among older adults with long-term SCI. The longitudinal approach may also increase our knowledge of the cause and effects of the associations found in this thesis, and future studies may identify additional associated factors.

The follow-up data collection also includes a qualitative approach to investigate the participants' perceptions of changes over time. Future studies will thereby provide an understanding of the self-perceived aging process among older adults with long-term SCI.

All of the participants in the SASCIS were recruited from the same geographical area and had received parts of their rehabilitation at the same SCI Unit. National and international comparisons, preferably in multicenter studies, would increase the generalizability of our findings. The established collaboration with researchers in Canada offers opportunities for cross-national comparisons.

Future studies should focus on the perceived problems related to neurogenic bowel and bladder dysfunction, spasticity and pain. Treatment effects and the frequency and duration of these SHCs are research areas that also require further studies.

Specific studies of the experiences of being a partner or family member of someone with long-term SCI would add a valuable dimension to our understanding of the life situation of older adults with long-term SCI.

Future studies should also focus on the perceived importance of a physically active lifestyle, and facilitators and barriers to participation in LTPA. This knowledge can in turn be used to understand the large variation in LTPA participation among older adults with long-term SCI, and to design intervention studies aiming to increase participation in LTPA. The development of international evidence-based SCI-specific physical activity guidelines[115] will form the foundation for such studies.

Populärvetenskaplig sammanfattning

På ett ögonblick kan livet förändras och stora delar av vardagen kan bli en utmaning. Detta är en upplevelse som delas av många av de nästan 300 personer som varje år drabbas av en ryggmärgsskada i Sverige. Ryggmärgen är förbindelsen mellan hjärnan och kroppen och ligger skyddad inuti vår kotpelare. Skador på ryggmärgen kan uppstå vid olyckor eller genom sjukdomar i ryggmärgen. Beroende på skadans omfattning och var den är lokaliserad drabbas personen av varierande grad av påverkan på motorik och känsel nedanför skadan. Skadan leder även ofta till mindre synliga funktionsnedsättningar, såsom svårigheter att styra blås- och tarmtömning, smärta och spasticitet (ofrivillig muskelaktivitet). Det finns idag ingen bot för en skadad ryggmärg men med korrekt akut omhändertagande, rehabilitering och stöd från samhället kan en person med ryggmärgsskada leva ett aktivt och rikt liv utifrån de förutsättningar som skadan medför.

En ryggmärgsskada var tidigare förknippad med en kort överlevnadstid. Tack vare stora framsteg inom sjukvård och rehabilitering lever idag många personer länge med sin skada. Trots detta vet vi väldigt lite om hur det är att bli äldre och leva länge med en ryggmärgsskada. Det övergripande syftet med denna avhandling var därför att beskriva livssituationen bland äldre personer som levt länge med en ryggmärgsskada. Specifikt undersöks skaderelaterade följdtillstånd, självständighet i vardagen, depressiva symptom, deltagande i fysisk aktivitet och livstillfredsställelse.

Avhandlingen är del av ett stort forskningsprojekt som följer personer med ryggmärgsskada över tid. Alla 123 deltagare (36 kvinnor och 87 män) var vid studiens start minst 50 år gamla och hade levt med en ryggmärgsskada i minst tio år. Data samlades in vid intervjuer och undersökningar i deltagarnas hem. Projektet har fått namnet Swedish Aging with Spinal Cord Injury Study (SASCIS) och är den första studien i norra Europa som syftar till att öka kunskapen om äldre personer som levt länge med en ryggmärgsskada. Målet är att på sikt skapa uppföljningsprogram och rehabiliteringsinsatser skräddarsydda för just den här gruppen.

Denna avhandling baseras på den första datainsamlingen (år 2011-2012) i SASCIS. Studiedeltagarna hade en medelålder på 63 år och hade levt i genomsnitt 24 år med en ryggmärgsskada. Den person som haft sin skada längst tid drabbades av skadan för 56 år sedan. De flesta av deltagarna hade fått sin ryggmärgsskada genom en

olycka och nästan en tredjedel hade en komplett skada, vilket innebär total förlust av känsel och motorik nedanför skadenivån. Strax över hälften av deltagarna levde i en parrelation och en tredjedel arbetade. Det stora flertalet använde hjälpmedel i vardagen, såsom rullstol eller rollator, och två tredjedelar hade någon form av assistans. Något oväntat beskrev färre än hälften av deltagarna problem med tarm, blåsa och spasticitet. Detta representerar en lägre förekomst av dessa skaderelaterade följdtillstånd än vad tidigare studier visat. Däremot upplevde två tredjedelar måttlig till svår smärta. Smärtan hade dock inget samband med deltagarnas självständighet i vardagen, deras deltagande i fysisk aktivitet eller deras livstillfredsställelse. De uppvisade generellt en relativt hög självständighet i vardagen, där skadans omfattning och förekomst av spasticitet var de viktigaste faktorerna för förmågan att självständigt kunna utföra vardagliga aktiviteter.

Förekomsten av sannolik depression var låg bland deltagarna, men nästan en tredjedel uppvisade någon form av depressiva symptom. Det fanns ett samband mellan deras psykiska mående och potentiellt påverkbara faktorer som neuropatisk smärta, deltagande i fysisk aktivitet och psykologiska resurser, såsom känsla av sammanhang och copingstrategier. Känsla av sammanhang står för förmågan att förstå och hantera motgångar, och att känna sig motiverad att ta sig an dem. Bland studiedeltagarna var denna förmåga starkt sammankopplad med färre depressiva symptom. Deltagarna skattade generellt en stark känsla av sammanhang, vilket tyder på att de har anpassat sig väl till att leva med en ryggmärgsskada.

Graden av fysisk aktivitet var låg och det stora flertalet av deltagarna nådde inte upp till den nivå av fysisk aktivitet som har positiva effekter på hälsan. Det visade sig att kvinnor, äldre deltagare, rullstolsanvändare och yrkesarbetande personer var mindre fysiskt aktiva än män, yngre deltagare, de som var gående och de som inte arbetade. Fler studier behövs för att undersöka faktorer som kan påverkas och därigenom öka den fysiska aktivitetsnivån bland äldre personer som levt länge med ryggmärgsskada.

Slutligen visade avhandlingen att studiedeltagarna var generellt nöjda med sin livssituation. I motsats till vad många skulle kunna tro spelade skadans omfattning ingen avgörande roll för hur nöjda deltagarna var med livet. Den enskilt viktigaste faktorn för en hög livstillfredsställelse var istället att leva i en parrelation.

Sammanfattningsvis visar resultaten att äldre personer som levt länge med ryggmärgsskada kan leva ett gott liv. Uppföljningsprogram riktade till dessa personer bör inkludera bedömning av smärta och depression, och deltagande i fysisk aktivitet bör utvärderas och uppmuntras. Resultaten tyder på att åtgärder för att främja psykisk hälsa bör inriktas på individens psykologiska resurser, smärthantering och deltagande i fysisk aktivitet. Avhandlingen bidrar med helt ny kunskap som är ett första steg mot att skapa rehabiliteringsinsatser skräddarsydda för äldre personer som levt länge med ryggmärgsskada.

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Appendix

Study-specific questionnaire for the SASCIS.

Journaldata/personuppgifter

Initialer					Löpnr
Ålder	Kön	Neurologisk nivå	AIS	Ålder vid skadetillfälle	Skadedatum
Skadeorsak					
Annan funktionsnedsättning					

Familjesituation, boende och sociala stödinsatser

Civilstånd	Barn
Boende	
Stödinsatser/hjälpbehov ex hemtjänst, personlig assistans	

Arbete/sysselsättning, utbildning

Arbete	%
Sjukersättning	%
Nuvarande sysselsättning/hobby	Folkpension (ja/nej)
Utbildning	

Huvudsaklig hjälpmedelsanvändning

Inomhus	Utomhus
Gånghjälpmedel (G)/manuell rullsol (M)/eldriven rullstol (E)	

Sjukdomar

Hjärtsjukdom	Behandling
Hypertension	Behandling
Dyslipidemi	Behandling
Diabetes	Behandling
Psykisk ohälsa	Behandling
Tumörsjukdom	Behandling

Sjukdomar före skada

	Behandling	Kontinuerlig behandling/ sjukvårdskontakt

Skaderelaterade följdtillstånd

Tarmregim	Problem med tarmen/behandling
Blåsregim	Problem med blåsan/behandling
Spasticitet (ja/nej), lokalisation	Behandling

Smärta/värk

Rörelseapparaten (ja/nej), lokalisation	Behandling
Neurogen smärtproblematik (ja/nej), lokalisation	Behandling

Skattning av smärtans svårighetsgrad (Visuell Analog Skala; VAS)

Rörelseapparaten

Ingen smärta Värsta tänkbara smärta

Neurogen smärtproblematik

Ingen smärta Värsta tänkbara smärta

Levnadsvanor

Fysisk aktivitet

Huvudsaklig motionsform	
Antal gånger per vecka, tidsåtgång	

Kost: Vad består Dina måltider vanligtvis av?

Frukost	Lunch	Middag/kvällsmat	Mellanmål

Hur ofta äter/dricker Du?

	Sällan/aldrig	Någon till några gånger i månaden	En gång i veckan	Flera gånger i veckan
Vegetariskt som huvudrätt				
Fisk/skaldjur/kyckling som huvudrätt				
Kött (nöt, fläsk) som huvudrätt				
Snabbmat				
Färdiglagad mat				

Färska grönsaker				
Färsk frukt/bär				
Godis/kakor/glass/chips mm				
Läsk/sötade drycker				

Tobak

	Aldrig	Enstaka tillfällen	Någon gång i månaden	Någon gång i veckan	Flera gånger i veckan	Dagligen
Hur ofta röker Du?						
Antal cigaretter						
Har Du tidigare varit daglig rökare?			Slutade år			
Använder Du andra tobaksprodukter? Hur ofta och hur mycket?						

Alkohol

	Aldrig	Enstaka tillfällen	Någon gång i månaden	Någon gång i veckan	Flera gånger i veckan	Dagligen
Hur ofta dricker Du alkohol?						
Hur många glas dricker Du en typisk dag då Du dricker alkohol?						
1-2 glas	3-4 glas	5-6 glas	7-9 glas	10 eller fler glas		
1 glas=45 cl folköl/33 cl starköl/1 glas vin/1 litet glas starkvin/4 cl starksprit.						

Hur nöjd är Du med Dina nuvarande levnadsvanor?

Inte alls nöjd 1	2	3	4	Mycket nöjd 5

In an instant, life can change and many everyday activities become a challenge. This experience is shared by many of the almost 300 men and women who sustain a spinal cord injury in Sweden each year. But what happens many years after the injury, and when signs of aging start to appear? This thesis aims to describe and understand aspects of the life situation of older adults with long-term spinal cord injury in southern Sweden.

The results are overall positive, showing that this population exhibit a relatively high level of physical independence, a low presence of probable depression and are generally satisfied with their lives. However, the high occurrence of pain and the low participation in physical activity are cause for concern. The results offer incentives to apply a proactive approach in clinical rehabilitation medicine. Pain and depressive symptoms should be routinely evaluated, and participation in physical activity assessed and encouraged. Measures focusing on psychological resources, pain management and physical activity may promote mental health, and facilitating social interaction and meaningful activities may support high levels of life satisfaction. The results serve as a starting point for an increased understanding of the life situation of older adults with long-term spinal cord injury in Sweden, and can be used to inform rehabilitation planning and provide routines for follow-up.

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