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*Published in:*  
PM&R

*DOI:*  
[10.1016/j.pmrj.2015.10.014](https://doi.org/10.1016/j.pmrj.2015.10.014)

2016

*Document Version:*  
Peer reviewed version (aka post-print)

[Link to publication](#)

*Citation for published version (APA):*  
Jørgensen, S., Iwarsson, S., Norin, L., & Lexell, J. (2016). The Swedish Aging with Spinal Cord Injury Study (SASCIS): Methodology and initial results. *PM&R*, 8(7), 667-677. <https://doi.org/10.1016/j.pmrj.2015.10.014>

*Total number of authors:*  
4

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LUND UNIVERSITY

PO Box 117  
221 00 Lund  
+46 46-222 00 00

# **The Swedish Aging with Spinal Cord Injury Study (SASCIS): Methodology and initial results**

**Sophie Jörgensen, MD, Susanne Iwarsson, PhD, reg. OT, Lizette Norin, BSc, reg. OT,  
Jan Lexell, MD, PhD**

**S.J.** Department of Health Sciences, Lund University, Lund, and Department of Neurology and Rehabilitation Medicine, Skåne University Hospital, Lund, Sweden

**S.I.** Department of Health Sciences, Lund University, Lund, Sweden

**L.N.** Department of Health Sciences, Lund University, Lund, Sweden

**J.L.** Department of Health Sciences, Lund University, Lund, and Department of Neurology and Rehabilitation Medicine, Skåne University Hospital, Lund, Sweden

Running title: Aging with spinal cord injury

Funding sources: This study was funded by the Swedish Research Council, Norrbacka-Eugenia Foundation, Promobilia Foundation, the Research Fund of Neuro Sweden, Gun och Bertil Stohne's Foundation, the Ribbingska Foundation in Lund, and the Queen Victoria and Gustaf V's Freemason's Foundation. The study was accomplished within the context of the Centre for Ageing and Supportive Environments (CASE) at Lund University, funded by the Swedish Council for Working Life, Public Health and Welfare (Forte).

# **The Swedish Aging with Spinal Cord Injury Study (SASCIS): Methodology and initial results**

## **ABSTRACT**

**Background:** Advances in acute treatment, psychiatric care and rehabilitation have improved survival greatly after spinal cord injury (SCI) and increased longevity. This has led to a need for an in-depth understanding of factors associated with healthy aging in people with long-term SCI.

**Objective:** To present the methodology and initial results of the Swedish Aging with Spinal Cord Injury Study, a longitudinal cohort survey targeting older adults with long-term SCI.

**Design:** Cross-sectional cohort study.

**Setting:** Home and community settings.

**Participants:** People aged 50 years or older with SCI for at least ten years.

**Methods:** Data were collected through interviews and assessments during home visits, and from the participants' medical records.

**Main outcome measurements:** Study-specific protocol with custom-designed questions, and validated generic and SCI-specific assessment tools focusing on functioning, disability, health, well-being, lifestyle, and personal and environmental factors.

**Results:** Of 795 potential participants, 184 matched the inclusion criteria and the final sample comprised 123 participants (67% response rate; 36 women and 87 men, mean age  $63 \pm 9$  years, mean time since injury  $24 \pm 12$  years). Traumatic SCI accounted for 62% and 31% had sustained a complete SCI. A majority was married or had a partner, and used some form of assistance and/or mobility device. Thirty-five percent were working full-time or part-time. Based on the American Spinal Injury Association Impairment Scale (AIS), 3 groups of SCI severity were formed. There were no significant differences in chronological age, marital status or vocational situation between the tetraplegia AIS A-C group ( $n=22$ ), the paraplegia AIS A-C group ( $n=41$ ) and the all AIS D group ( $n=60$ ). Participants in the all AIS D group were significantly older at injury, had a shorter time since injury and were less likely to use mobility devices compared to the other 2 groups.

**Conclusion:** These baseline data of the Swedish Aging with Spinal Cord Injury Study provide a description of older adults with long-term SCI. Forthcoming studies and subsequent follow-ups will generate new insights into factors that promote healthy aging, minimize disability and enhance participation, quality of life and life satisfaction in people aging with long-term SCI.

**KEY WORDS**

Activities of daily living; Aging; Disability evaluation; International Classification of Functioning, Disability and Health; Outcome assessment (Health care); Patient outcome assessment; Questionnaires; Quality of life; Rehabilitation; Spinal cord injuries

## INTRODUCTION

Spinal cord injury (SCI) can be a life-altering event leading to long-term disability [1]. In 2007, the worldwide incidence of traumatic SCI (TSCI) was estimated at 23 cases per million, corresponding to 40 per million in North America and 16 per million in Western Europe [2]. In Sweden, with a population of approximately 9 million people, around 5000 are living with the long-term consequences of a TSCI [3]. The incidence of nontraumatic SCI (NTSCI) is more difficult to estimate. NTSCI are considered more common than TSCI and affect mostly older people [4]. A recent review on NTSCI reported an incidence of 76 new cases per million in North America [5].

Advances in acute treatment, physiatric care and rehabilitation have improved survival greatly after SCI and increased longevity [6]. Still, life expectancy is lower than in noninjured populations, due to higher mortality rates among people with severe SCI and those injured at older ages [4,6]. As people with a disability are growing older, there is evidence of an accelerated aging of organ systems, exacerbating their disability [7]. For people with SCI, age itself is associated more closely with increased dependence in daily activities than level and completeness of injury [8]. SCI-related impairments and activity limitations can increase over time [9], and superimposed disabilities can be experienced 15 to 20 years earlier in people with SCI than in noninjured populations [10,11]. Even small changes in functioning can therefore have far-reaching consequences for their performance and engagement in everyday life [11]. Moreover, the interaction with the surrounding physical and social environment considerably impacts disability of people with SCI [7,10].

There are various examples how SCI-related impairments accompanied by accelerated aging can increase the risk of developing secondary complications and lead to premature death [12,13]. Common causes of death among individuals with long-term SCI, such as CVD, respiratory diseases and cancer, are linked to potentially preventable lifestyle risk factors like diabetes, smoking, obesity and inactivity [14]. When the consequences of aging are combined with a neurological disability, focus on modifiable lifestyle risk factors might be even more important to maintain health and prevent secondary complications.

SCI also is accompanied by changes in psychological and psychosocial aspects of daily living [6]. Studies indicate that depression rates increase with age and time since injury [6], but the evidence is inconsistent [13]. Lower quality of life (QoL) [15] and life satisfaction [16] are reported after a SCI. However, increasing age and time since injury also are reported to have a positive effect on aspects of subjective well-being [17]. In the general population, personal factors and psychological resources, such as sense of coherence (SOC)

and coping strategies, are associated positively with QoL and health [18]. In people with SCI, greater acceptance and less dependent behavior, indicating positive coping resources, have been linked to a better health-related QoL (HRQoL) and psychosocial adaptation [19,20]. Even though positive interactions between psychological resources, mental health and well-being have been suggested in people with SCI, further studies are needed to describe these associations in detail in people aging with long-term SCI [21].

The physical and social environment influence participation in daily life in people with disabilities, but this has been scarcely addressed in people with SCI [22]. In one of very few studies, Whiteneck et al [23] reported that environmental barriers affect life satisfaction in people with SCI, and that encountering environmental barriers is related more strongly to life satisfaction than to participation. This implies that people with SCI, even if they can overcome environmental barriers, are negatively affected by facing them. In addition, people with SCI often are dependent on assistive technology in daily life. Yet, our knowledge of the person-environment (P-E) dynamics among older adults with long-term SCI is practically nonexistent. Research on housing, neighbourhoods and health in people aging with SCI is needed to attain an enhanced understanding of the interaction between the capacity of the individual and the demands of the environment. As such interaction influences behaviour and adaptation [24,25], elucidation of the P-E dynamics among people aging with SCI can be used to develop more effective rehabilitation interventions.

Despite increased attention to research on aging with SCI over the past decades, many questions remain unanswered [6]. Long-term longitudinal studies from, for example, the US, Canada and United Kingdom have reported on a variety of aspects of aging with SCI [26,27,28]. However, due to cultural and contextual differences it is challenging to relate findings across studies and different national contexts. From a Northern European perspective, there are no comprehensive studies with longitudinal data on older adults many years post SCI. Therefore, to contribute to our knowledge of aging with long-term SCI, we initiated the Swedish Aging with Spinal Cord Injury Study (SASCIS). In the SASCIS, we focus on functioning, disability, health, well-being, lifestyle, and personal and environmental factors, targeting people 50 years of age and older with SCI for ten years or more. Given the global rise in older adults with SCI and the need for an in-depth understanding of factors associated with healthy aging in people with long-term SCI, the SASCIS and forthcoming studies will provide knowledge of clinical and scientific as well as societal importance.

The objectives of the present study are to: i) present an overview of the research design, recruitment procedure, data collection and assessment tools of the SASCIS, ii)

compare the participants and the nonparticipants regarding background data, and iii) describe baseline sociodemographics and injury characteristics of older adults with long-term SCI.

## **METHODS**

### **Research design**

The SASCIS is a longitudinal cohort survey targeting community-dwelling older adults (50 years of age and older) with long-term SCI (at least ten years) residing in southern Sweden (current population approx. 1,770,000). This would enable us to recruit people that are in a stable phase post SCI who experience the effects of aging. A five-year follow-up is planned and will be followed by further longitudinal studies.

The SASCIS was designed based on the International Classification of Functioning, Disability and Health (ICF) conceptual framework [29]. The ICF provides a bio-psycho-social approach to neurologic disability [30], allowing aspects of functioning, disability and health to be studied. As for research on housing, neighbourhoods and health along the process of aging, the ecological theory of aging [24,25] including the notion of person-environment (P-E) fit and the docility hypothesis [31] were applied. The docility hypothesis states that “the less competent the individual, the greater the impact of environmental factors on that individual”, acknowledging that those with more impairments are more vulnerable to environmental demands [31].

### **Ethical considerations**

The SASCIS was approved by the Regional Ethical Review Board in Lund, Sweden (No. 2010/692). The Helsinki declaration for research on humans was followed. Before enrolment, all participants signed a written informed consent form.

### **Participants**

Participants were recruited through the clinical databases available in the SCI Unit at Skåne University Hospital, Sweden. These databases include people with SCI that have been in contact with the SCI Unit over the past four decades. The two main inclusion criteria were: i) age 50 years or older and ii) TSCI or acquired nonprogressive NTSCI for at least ten years. At the time of recruitment (year 2011), the databases comprised 795 people (including those deceased) (Figure 1). A total of 184 people finally matched the inclusion criteria and were invited to participate. Of these, 123 accepted the invitation (response rate 67%); fifty-one declined and ten did not respond despite several attempts to make contact.



## *Figure 1*

### **Data collection procedure**

Data were collected by two of the authors (S.J. and L.N.) through structured interviews and assessments during visits in the participants' homes (n=122) or at another place (n=1), and from the participants' medical records. A study-specific protocol with custom-designed questions was used together with eight validated generic and four SCI-specific assessment tools. Five assessment tools were sent to the participants prior to the home visits, and reviewed and collected during the visits.

After the interview and assessments, anthropometric and clinical measurements were obtained. The home visits lasted for about 120 minutes (range 110 to 240 minutes). All participants also were asked to go through blood analyses at their local medical centre.

### **Data obtained from medical records and the study-specific protocol**

The following sociodemographic and injury-related data were registered: gender, age, marital status, vocational situation, housing, use of assistance, use of mobility aids, age at injury, time since injury, cause of injury, and level and severity of injury. We also collected data on secondary conditions including bowel and bladder functioning and related impairments (e.g. incontinence, constipation, diarrhoea, urgency, frequent urinary tract infections), neuropathic and nociceptive pain, spasticity, diagnosed and treated co-morbidities (e.g. heart disease, hypertension, dyslipidemia, diabetes, psychiatric disorders and cancer), prescribed medications and lifestyle-related factors including dietary habits, use of alcohol and tobacco, and engagement in physical activity.

### **Determination of injury severity**

The severity of injury was determined according to the American Spinal Injury Association Impairment Scale (AIS) [32]. The AIS is a standard method used to classify the neurological impairment after SCI into one of five categories: AIS A (complete injury); AIS B (sensory incomplete injury); AIS C (motor incomplete injury, more than half of key muscle functions below the neurological level have a muscle grade 2 or less); AIS D (motor incomplete injury, at least half of key muscle functions below the neurological level have a muscle grade 3 or more); AIS E (normal sensory and motor function). On the basis of the level of the lesion, i.e. cervical or thoracic/lumbar/sacral, the SCI is classified as tetraplegia or paraplegia. To allow

for further comparisons between subgroups of participants, three SCI severity groups were formed: i) tetraplegia AIS A-C, ii) paraplegia AIS A-C, and iii) all AIS D.

### **Assessment tools**

In Table 1, the eight generic and four SCI-specific assessment tools used in the SASCIS (all administered in Swedish) are presented according to the part and component of the ICF that they are primarily related to [33]. The twelve assessment tools were selected following an extensive literature search and the authors' experiences from rehabilitation outcomes research. The assessment tools complement each other, as one single tool may not capture all aspects of a specific ICF component. Many of the tools were developed prior to the introduction of the ICF and can be therefore related to several ICF components, and also comprise items that are not readily associated with specific domains in the ICF. For example, items in tools rating an individual's life satisfaction can be related to the concept of participation (i.e. involvement in a life situation) as well as a broader subjective judgement upon a person's current life situation in relation to his/her own standards and expectations [34].

*Table 1*

#### ***Generic assessment tools***

*Craig Hospital Inventory of Environmental Factors (CHIEF)* The CHIEF [35] captures perceived impact of environmental barriers among people with and without disabilities. It consists of 25 items that focus on the frequency and magnitude of barriers within five domains of environmental factors: policies, physical and structural, work and school, attitudes and support, services and assistance. Respondents rate the frequency of the occurrence of the barriers in the 25 items on a five-grade scale: daily, weekly, monthly, less frequently than once per month, and never. If they encounter a barrier, its magnitude is rated on a two-grade scale according to whether it is small or large. The CHIEF has shown high test-retest reliability (Intraclass Correlation Coefficient, ICC = 0.93) and high internal consistency (Cronbach's alpha = 0.93) in people with disabilities, including SCI [35]. The current Swedish version of CHIEF has been used in people with late effects of polio [36].

*Geriatric Depression Scale (GDS)* The GDS [37] is a screening instrument for depression among older adults. The original version consists of 30 questions (response options yes or no) and has been shown to be internally consistent, reliable, valid and sensitive [37]. The GDS

has subsequently been shortened to 15 questions. In the current Swedish version, five questions about physical health have been added, yielding 20 questions [38]. If the total score is 6 or more, depression should be considered.

*Housing Enabler (HE)* The HE [39] was developed in Sweden to capture housing accessibility based on the notion of the P-E fit [24,25]. The instrument consists of two components: a personal component assessing functional limitations (twelve items) and dependence on mobility devices (two items) as present/not present, and an environmental component where barriers (defined according to current national standards and guidelines for housing design) in the exterior surroundings, entrances and indoor environment (161 items) are dichotomously assessed. These assessments are followed by an analysis of the magnitude of accessibility problems based on predefined severity ratings (0-4); the greater the total score, the more accessibility problems. The HE has demonstrated construct validity [40] and overall moderate to good inter-rater reliability [41]. The instrument also has been tested for inter-rater reliability in occupational therapy practice in a cross-Nordic setting, with a mean percentage agreement of paired raters exceeding 80% for both components [42]. The HE rests on extensive research and has been used in large studies involving aging populations in different countries [43].

*Impact on Participation and Autonomy (IPA)* The IPA [44] captures perceived aspects of participation and autonomy in people with chronic disorders. These aspects are rated in five domains (31 items): autonomy indoors (seven items), family role (seven items), autonomy outdoors (five items), social relations (six items), and work and education (six items), using a five-point rating scale (from 1 = 'very good' to 5 = 'very poor'); lower scores indicate better participation [45]. Perceived problems in nine areas (mobility, self-care, family role, financial situation, leisure, social relations, helping people, work and education) are measured on a three-point rating scale (from 0 = 'no problems' to 2 = 'severe problems'); lower scores indicate fewer problems. The instrument is reliable and valid in people with chronic disorders, including SCI [45]. Internal consistency and test-retest reliability are good with Cronbach's alpha >0.81 [44,45] and ICC between 0.83 and 0.91, and convergent and discriminant validity has been supported [45]. A Swedish version has been tested among individuals with SCI [46]. One item (helping and supporting other people, in the social life and relationship subscale), has been added to the original IPA, thus comprising 32 items; the current Swedish version of IPA (32 items) has been used in people with late effects of polio [47].

*Life Satisfaction Questionnaire (LiSat)* The LiSat [48] was developed in Sweden and captures global satisfaction with life in one item and domain-specific satisfaction in ten items: vocational situation, financial situation, leisure situation, contacts with friends and acquaintances, sexual life, self-care, family life, partnership relation, and somatic health and psychological health. There are six response options, from ‘very satisfied’ (response option 6) to ‘very dissatisfied’ (response option 1); greater ratings reflect greater life satisfaction. Population-based Swedish reference values enable comparisons between people with disabilities and the general population [49]. The LiSat has shown satisfactory internal consistency (Cronbach’s alpha 0.75) in SCI [50] and has been used in studies of individuals with SCI, both in Sweden [51] and internationally [52].

*Satisfaction With Life Scale (SWLS)* The SWLS [34] provides a global measure of satisfaction with life and consists of five questions rated on a seven-point Likert scale, ranging from ‘strongly agree’ (response option 7) to ‘strongly disagree (response option 1)’. The scores are summed to a total score ranging from 5 to 35, where a greater score reflects greater life satisfaction; a score of 20 represents the mid-point between satisfied and dissatisfied. The SWLS has demonstrated good convergent validity with different measures of subjective well-being and life satisfaction [53], and good internal consistency (Cronbach’s alpha 0.83) in people with SCI [50]. For comparison, normative data from around 3,000 Swedish people are available [54]. The current Swedish version of SWLS has been used in people with traumatic brain injury [55].

*Sense of Coherence (SOC-13) scale* The SOC-13 [56] assesses the three dimensions of the Sense of Coherence (SOC) concept: comprehensibility (five items), manageability (four items) and meaningfulness (four items) [57]. The SOC-13 is a 7-point Likert scale ranging from agreement to disagreement with anchoring phrases at each end representing strong and weak SOC, respectively. The total score ranges from 13 to 91, with greater scores indicating a stronger SOC. The scale has shown acceptable face validity and high internal consistency with Cronbach’s alpha ranging from 0.70 to 0.92 [57]. The SOC-13 is available in various languages and there are Swedish reference values for comparison [58,59].

*Wheelchair User’s Shoulder Pain Index (WUSPI)* The WUSPI [60] captures shoulder pain in wheelchair users and its impact on everyday activities. The instrument consists of 15 items

and covers a variety of common everyday activities performed by wheelchair users: transfers (four items), wheelchair mobility (two items), self-care (five items) and general activities (four items). The participant is asked to rate the pain experienced on a Visual Analogue Scale (VAS), ranging from 'no pain' to 'worst pain ever experienced'; the greater the VAS score, the greater is the pain. The instrument has shown high internal consistency (Cronbach's alpha 0.97) [60] and high test-retest reliability (ICC 0.99 for the total score) [61]. The current Swedish version of WUSPI has been used in people with thoracic SCI [62].

### ***SCI-specific assessment tools***

*Physical Activity Recall Assessment for People with Spinal Cord Injury (PARA-SCI)* The PARA-SCI [63] was developed in Canada and measures the frequency, type, duration and intensity of physical activity (PA) in people with SCI (primarily wheelchair users). The PARA-SCI captures leisure time PA (e.g. sports), lifestyle PA (e.g. dressing, grocery shopping) and cumulative PA (leisure time PA and lifestyle PA). Test-retest reliability is comparable to other measures of PA and there is evidence of construct validity [63,64]. A Swedish version of PARA-SCI has been developed in collaboration with the developers [65].

*Spinal Cord Independence Measure (SCIM)* The SCIM [66] is a comprehensive functional ability rating scale that captures the subjective value of an activity, the time required and the level of difficulty performing the task [67]. The third version, SCIM III, covers 19 areas of activities of daily living (ADL) grouped into three subscales: self-care (score 0-20), respiratory and sphincter management (score 0-40), and mobility (score 0-40) [68]. The total score ranges from 0-100; a greater score indicates less activity limitations and greater independence. A large multicenter study [68] has investigated the psychometric properties of SCIM III in a heterogeneous sample of 425 patients with TSCI or NTSCI from six countries in North America, Europe and the Middle East. Inter-rater reliability was reflected in >80% agreement of paired raters for most items (74.5% to 96.2%), kappa values of 0.63 to 0.82, ICC >0.94 for the total score and all subscales, and Cronbach's alpha values >0.7 for all subscales and 0.85 for the total score. Rasch analysis [69] indicates that all subscales are valid and reliable measures of the ability to perform relevant ADL. The SCIM III is more sensitive to functional changes in the SCI population than other assessment instruments, such as the FIM [68]. The SCIM has been suggested to be the primary outcome measure of functional recovery after SCI across the world [70].

*Spinal Cord Injuries Quality of Life Questionnaire (SCI QL-23)* The SCI QL-23 [71] was developed in Sweden. It was derived from items in the Sickness Impact Profile (SIP) and the Hospital Anxiety and Depression (HAD) scale) and combined with questions regarding SCI-related problems. The SCI QL-23 captures functioning (ten items assessing physical and social limitations), mood (six items assessing distress and depressive symptoms), SCI-related problems (six items) and global HRQoL (rated on a visual analogue scale) [72]. Scores are calculated in the four domains and transformed into a 0-100 scale [19]. Lower scores indicate better QoL in all scales except for the global HRQoL scale where greater scores indicate a better QoL. Content validity is supported by the inclusion of generic and SCI-specific aspects of physical and psychosocial functioning and well-being, as well as overall HRQoL [72]. Internal consistency for the four domains is high (Cronbach's alpha 0.85-0.86) [71], and sensitivity to clinically relevant functional differences and severities of SCI has been demonstrated [72].

*Spinal Cord Lesion-related Coping Strategies Questionnaire (SCL CSQ)* The SCL CSQ [73] was also developed in Sweden and captures acceptance (reevaluation of life values), fighting spirit (efforts to behave independently) and social reliance (tendency to be dependent on others) after SCI. It consists of twelve statements to be answered on a symmetrical four-point Likert scale, ranging from 1 (strongly disagree) to 4 (strongly agree). Domain scores are summed and then averaged. Scores range between 1 and 4 for each domain where higher scores indicate greater affirmation of the domain to coping.

### **Anthropometric and clinical measurements**

The participants' body weight was recorded with a portable scale for wheelchairs (Corina Medical MPWS 300, Rörvik, Sävsjö, Sweden) and their height was measured in the supine and, when possible, in the standing position. Waist circumference was measured at the umbilical level in the sitting, supine and, when possible, in the standing position. Sitting blood pressure was measured both manually and with an automatic device in the right arm (Boso Medicus, Germany). Blood samples of lipid profiles and fasting plasma glucose were obtained at the participants' local health care centre after an overnight fast.

### **Data quality control**

All data were coded and registered in Microsoft Excel and thereafter imported to the IBM SPSS Statistics version 22.0 for Windows to create a study-specific database. A quality

control process including a random selection of 10% of the cases was carried out to ensure that the database accurately reflected all collected data. Any discrepancies in the database were noted on a log sheet and subsequently corrected. Thereafter, an error rate was calculated; since the error rate was 0.51%, another 10% of the cases were subjected to quality control. As this resulted in a total error rate of 0.28%, the quality control process was considered complete. A validation of the data was also performed by checking for ranges, logical consistency and completeness. Missing or unclear data underwent a data cleaning process, using Data Clarification Forms. Any changes applied to the database during this cleaning process were noted on a log sheet. When the quality control process and data cleaning were completed, the database was locked.

### **Statistical analysis**

In the present study, sociodemographics and injury characteristics are presented by means of descriptive statistics. Differences between gender, participants and nonparticipants, participants with TSCI and NTSCI, and the 3 groups of SCI severity were analyzed using the Kruskal-Wallis test, the Mann-Whitney U-test or the Chi-square test, where appropriate.

## **RESULTS**

### **Participants and drop-out analysis**

Background data for the 123 participants and the 61 nonparticipants are presented in Table 2. Men were in a majority ( $n=87$ ; 71%). The mean age of all participants was 63 years (50-89), and they were on average 39 years (7-74) at the time of injury. The mean time since injury was 24 years (10-56). TSCI accounted for 62% ( $n=76$ ) and the most common cause was transportation-related accidents. About one third of the participants ( $n=38$ ; 31%) were classified as AIS A (complete injury) and 39% ( $n=48$ ) had sustained a cervical injury. There were no significant differences between the participants and the nonparticipants regarding gender, chronological age, age at injury, time since injury, cause of injury (TSCI/NTSCI), severity (complete/incomplete) and level of injury (tetraplegia/paraplegia).

### *Table 2*

### **Descriptive findings**

In Table 3, data on the level and severity of injury among the 123 participants are presented.

The most common type of injury was paraplegia AIS D ( $n=34$ ; 28%). Twelve percent of the participants ( $n=15$ ) had sustained a complete cervical injury but none were strictly ventilator-dependent. The tetraplegia AIS A-C group included 22 participants (18% of the sample; 15 AIS A, four AIS B and three AIS C), the paraplegia AIS A-C group included 41 participants (33%; 23 AIS A, eight AIS B and ten AIS C) and the all AIS D group included 60 participants (49%), with injury levels ranging from C1-L5.

### *Table 3*

In Table 4, sociodemographics and injury characteristics for each of the 3 SCI severity groups are presented. More than half ( $n=65$ ; 53%) of the participants were living in a relationship (married/co-habiting/partner) and 35% ( $n=43$ ) were working full-time or part-time. Two-thirds of the participants used assistance ( $n=83$ ; 67%), mostly personal ( $n=36$ ; 29%) but also other forms of assistance, such as home-help service, personal security alarm, cleaning help, and a majority used some form of mobility device indoors ( $n=93$ ; 76%) and/or outdoors ( $n=108$ ; 88%).

There was no significant difference between men and women regarding chronological age, marital status, vocational situation, use of assistance, age at injury and time since injury. There were more women in the all AIS D group than in the paraplegia AIS A-C group ( $p=.044$ ). Participants with NTSCI were significantly older ( $p=.044$ ), were older at the time of injury ( $p<.001$ ) and had shorter time since injury ( $p<.001$ ).

There were no significant differences in chronological age, marital status or vocational situation between the 3 SCI severity groups. Comparing the all AIS D with the tetraplegia AIS A-C and the paraplegia AIS A-C, respectively, the all AIS D were more likely to have a NTSCI ( $p=.001$ ;  $p<.001$ ), less likely to use mobility devices indoors ( $p<.001$ ;  $p<.001$ ) and/or outdoors ( $p=.008$ ;  $p<.001$ ), were older at the time of injury ( $p=.001$ ;  $p=.013$ ) and had a shorter time since injury ( $p<.001$ ;  $p=.001$ ). There were no significant differences between the tetraplegia AIS A-C and the paraplegia AIS A-C. Participants in the tetraplegia AIS A-C were more likely to use assistance compared to the other two groups ( $p=.001$ ), but there was no significant difference between the paraplegia AIS A-C and the all AIS D regarding the use of assistance.

### *Table 4*



## DISCUSSION

The overall aim of the SASCIS is to generate new knowledge of a variety of aspects of living with SCI into later life and the challenges older adults with long-term SCI meet as they age. The baseline data collected and presented here will allow us, in forthcoming studies, to determine the influence of personal and lifestyle related factors, and environmental issues on disability, health, HRQoL and life satisfaction among older adults with SCI. As we plan for follow-up studies, we will be able to assess changes in various aspects over time.

The majority of the participants in the SASCIS were men, and the most common cause of TSCI was transportation-related accidents. This is in agreement with previous studies of people with SCI, regardless of age [4]. The most common causes of NTSCI were spinal tumours and spinal disk herniations, which is also in agreement with epidemiologic data from Western Europe and North America [5]. While TSCI often results in incomplete tetraplegia [74], the most common type of injury in our sample was incomplete paraplegia, as the result of the inclusion of NTSCI [5]. As none of the participants were strictly ventilator-dependent, our sample did not include those with the most pronounced disability.

With an average age of 63 years and close to 25 years post SCI, our participants were generally older and had lived longer with their SCI compared to those in previous cohort studies [10,12,13]. The mean age at injury of 39 years in our sample is, on the other hand, similar to that from the U.S. [4,74]. While there was a wide range of injury severity, a majority of the participants used assistance and some form of mobility device indoors and/or outdoors. More than half of the participants were living in a relationship and as many as 43 of those in working age ( $n=77$ ; 56%) were employed. Marital status and gainful employment are important aspects of QoL and life satisfaction, and will be an important area for future studies. All participants were community-dwelling, so further studies of environmental barriers and accessibility in housing and neighborhoods and the association with aspects of health, participation, HRQoL and life satisfaction will also be of importance.

Comparing the three injury severity groups, there were some obvious differences attributed to the overall disability, which will be accommodated in future studies. In such studies, comparisons with population-based reference values and data from other disability populations collected within our research environment will be made [75,76]. Already established international collaboration offers opportunities for cross-cultural comparisons of populations aging with SCI.

The SASCIS baseline data were collected through face-to-face interviews and direct assessments in the participants' homes. This procedure is by nature resource intensive

but has several advantages. It ensures a high data quality with minimal missing data. Furthermore, interviews, assessments and observations during home visits provide a unique insight into the participants' everyday life, as well as their feelings and concerns about aging with SCI. With two researchers present during the data collection, we were able to tailor the situation to suit the participants' needs, provide guidance if someone found it difficult to understand a question, and review the assessment tools that were sent to the participants prior to the home visit. Furthermore, the home visits were necessary to perform the objective housing accessibility assessment by means of the Housing Enabler.

We made great efforts to attain a high participation rate, including sending reminders and attempting telephone contact with all the nonrespondents. This resulted in a response rate of 67% of those matching the inclusion criteria (cf. Figure 1). As there were no significant differences between the participants and the nonparticipants regarding their age, age at injury, time since injury, injury level, completeness and cause of injury, our sample is likely to represent the population aging with SCI in southern Sweden.

Although this sample will provide a multifaceted in-depth description of aging with SCI there are some study limitations. The baseline data will be used in several studies to describe the current life situation of older adults with long-term SCI. However, follow-up data collection is required to evaluate the effects of age on different factors. All baseline data were collected using a study-specific protocol with custom-designed questions, and validated generic and SCI-specific assessment tools. Even though these tools included various aspects of health and well-being, the quantitative design limits our ability to explore long-term outcome from a truly person-centered perspective and the process by which the outcome has emerged. In the future, studies based on qualitative research interviews will therefore be conducted.

## **CONCLUSION**

The SASCIS is the first comprehensive study on aging with SCI in Sweden and these baseline data provide a description of older adults with long-term SCI. Forthcoming studies and subsequent follow-ups will broaden our understanding and generate new insights into factors that promote healthy aging, minimize disability and enhance participation, QoL and life satisfaction in people aging with long-term SCI. The results will thereby provide a foundation for the development of physiatric follow-up programs, and lifestyle as well as environmental interventions specific to this population.

## **ACKNOWLEDGEMENTS**

The authors are grateful to all participants. Björn Slaug, PhD, assisted in the data management, and Vibeke Horstmann, LicSc, provided valuable statistical advice.

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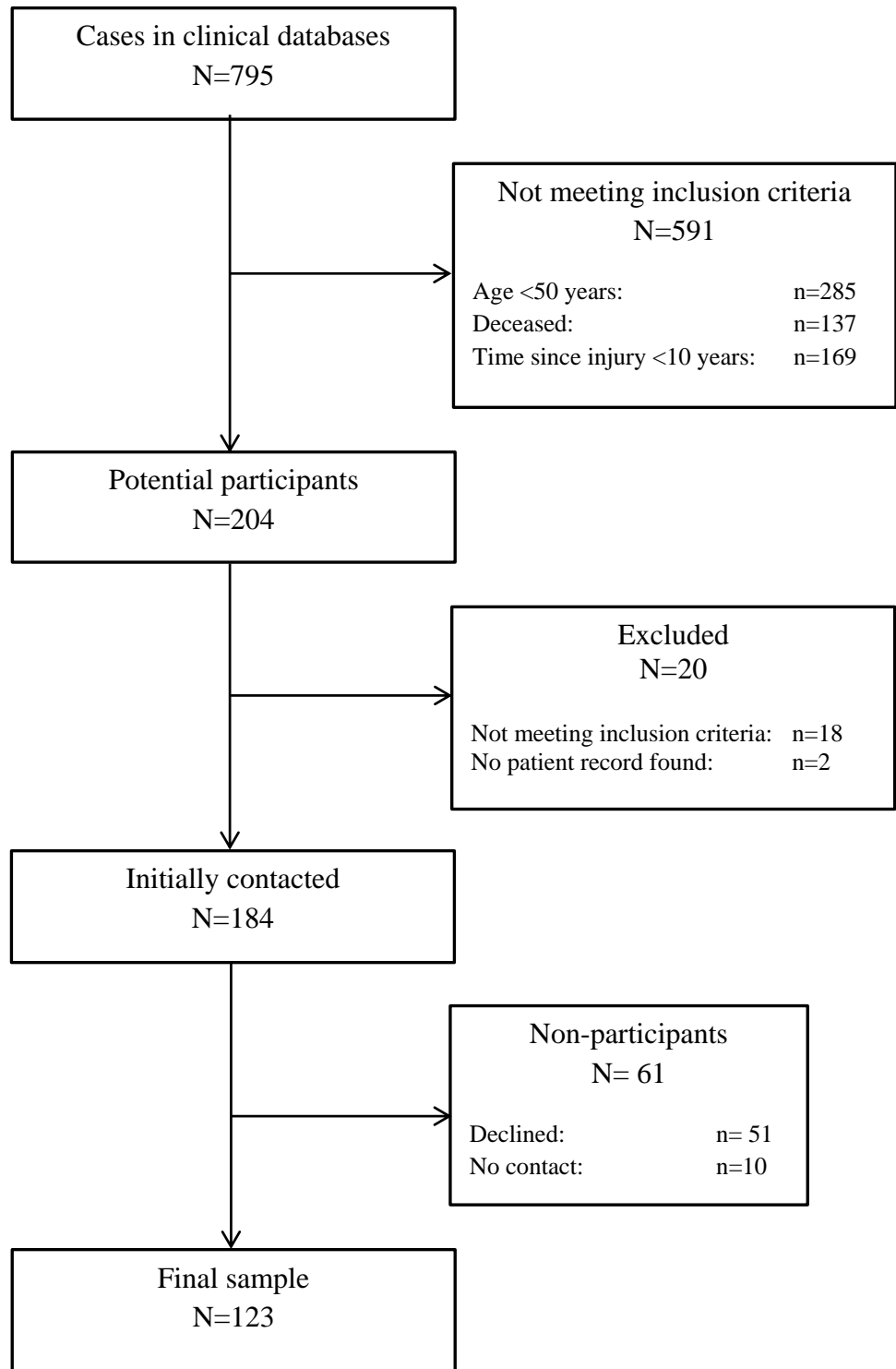
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**Figure 1.** The recruitment procedure of the Swedish Aging with Spinal Cord Injury Study (SASCIS).

**Table 1.** The validated generic and spinal cord injury-specific assessment tools used in the Swedish Aging with Spinal Cord Injury Study (SASCIS), and their relationship to the International Classification of Functioning, Disability and Health (ICF).

ICF Part	Functioning and Disability		Contextual Factors	
ICF Component	Body Functions & Structures	Activity & Participation	Environmental Factors	Personal Factors
<b>Generic assessment tool</b>				
*Craig Hospital Inventory of Environmental Factors (CHIEF) [35]			X	
Geriatric Depression Scale (GDS) [37]	X			
Housing Enabler (HE) [39]	X		X	
*Impact on Participation and Autonomy (IPA) [44]		X		
*Life Satisfaction Questionnaire (LiSat-11) [48]		X		
*Satisfaction With Life Scale (SWLS) [34]		X		
Sense of Coherence (SOC-13) scale [56]				X
*Wheelchair User's Shoulder Pain Index (WUSPI) [60]	X			
<b>Spinal cord injury-specific assessment tool</b>				
Physical Activity Recall Assessment for People with Spinal Cord Injury (PARA-SCI) [63]		X		
Spinal Cord Independence Measure (SCIM) [66]		X		
Spinal Cord Injuries Quality of Life Questionnaire (SCI QL-23) [71]	X	X		
Spinal Cord Lesion-related Coping Strategies Questionnaire (SCL CSQ) [73]				X

Numbers in brackets refer to the reference to the assessment tool (cf. References).

\*Indicates assessment tools that were sent to the participants prior to the interview and assessments, and reviewed and collected during the visit.

**Table 2.** Comparison between the participants and nonparticipants in the Swedish Aging with Spinal Cord Injury Study (SASCIS).

	Participants ( <i>n</i> =123)	Nonparticipants ( <i>n</i> =61)
Men	87 (71)	38 (62)
Women	36 (29)	23 (38)
Chronological age (years)	63 ±9; 50-89	65 ±10; 50-89
Age at injury (years)	39 ±16; 7-74	44 ±17; 17-76
Time since injury (years)	24 ±12; 10-56	21 ±11; 10-52
Traumatic injury	76 (62)	33 (54)
Complete injury	38 (31)	20 (33)
Tetraplegia	48 (39)	19 (31)
Paraplegia	75 (61)	42 (69)

Data are presented as *n* (%) and mean ± SD; range

There were no significant differences between the participants and nonparticipants regarding their gender, chronological age, age at injury, time since injury, cause of injury (TSCI/NTSCI), severity (complete/incomplete) and level of injury (tetraplegia/paraplegia).

TSCI=traumatic spinal cord injury; NTSCI=nontraumatic spinal cord injury

**Table 3.** Description of the severity and level of injury among the 123 participants in the Swedish Aging with Spinal Cord Injury Study (SASCIS).

	<i>n</i> (%)
Severity of injury	
AIS classification	
AIS A	38 (31)
AIS B	12 (10)
AIS C	13 (11)
AIS D	60 (49)
AIS E	0 (0)
Grouping of level and severity of injury	
C1-C4	16 (13)
AIS A	11 (9)
AIS B	2 (2)
AIS C	3 (2)
C5-C8	6 (5)
AIS A	4 (3)
AIS B	2 (2)
AIS C	0 (0)
T1-L5	41 (33)
AIS A	23 (19)
AIS B	8 (7)
AIS C	10 (8)
All AIS D	60 (49)
C1-C4	16 (13)
C5-C8	10 (8)
T1-L5	34 (28)

AIS = American Spinal Injury Association (ASIA) Impairment Scale [32]; For details regarding the AIS, see Determination of Injury Severity.

**Table 4.** Sociodemographics and injury characteristics of the 123 participants in the Swedish Aging with Spinal Cord Injury Study (SASCIS).

	Total ( <i>n</i> =123)	Tetraplegia AIS A-C ( <i>n</i> =22)	Paraplegia AIS A-C ( <i>n</i> =41)	All AIS D ( <i>n</i> =60)
Gender <sup>1</sup> ( <i>n</i> (%))				
Men	87 (71)	15 (68)	34 (83)	38 (63)
Women	36 (29)	7 (32)	7 (17)	22 (37)
Age (years; mean $\pm$ SD; median, range)	63 $\pm$ 9; 63, 50-89	60 $\pm$ 7; 59, 50-77	63 $\pm$ 9; 61, 50-78	65 $\pm$ 9; 64, 50-89
Age at injury <sup>1,2</sup> (years; mean $\pm$ SD; median, range)	39 $\pm$ 16; 38, 7-74	31 $\pm$ 13; 29, 17-62	36 $\pm$ 15; 32, 7-63	45 $\pm$ 16; 49, 12-74
Time since injury <sup>1,2</sup> (years; mean $\pm$ SD; median, range)	24 $\pm$ 12; 22, 10-56	30 $\pm$ 9; 29, 13-48	27 $\pm$ 12; 27, 10-56	20 $\pm$ 11; 15, 10-50
Cause of injury <sup>1,2</sup> ( <i>n</i> (%))				
Traumatic <sup>4</sup>	76 (62)	18 (82)	34 (83)	24 (40)
Non-traumatic <sup>5</sup>	47 (38)	4 (18)	7 (17)	36 (60)
Marital status ( <i>n</i> (%)) <sup>6</sup>	65 (53)	13 (59)	24 (59)	28 (47)
Vocational situation ( <i>n</i> (%))				
Working full-time or part-time	43 (35)	8 (36)	15 (37)	20 (33)
Disability pension	34 (28)	8 (36)	12 (29)	14 (23)
Old age pension	46 (37)	6 (27)	14 (34)	26 (43)
Type of housing				
One family house	67 (54)	11 (50)	22 (54)	34 (57)
Apartment	56 (46)	11 (50)	19 (46)	26 (43)
Residential location <sup>3</sup>				
Urban	78 (63)	18 (82)	20 (49)	40 (67)
Rural	45 (37)	4 (18)	21 (51)	20 (33)
Use of assistance <sup>2,3,7</sup> ( <i>n</i> (%))	83 (67)	22 (100)	27 (66)	34 (57)

Use of mobility devices (*n* (%))

Indoors<sup>1,2</sup>

Manual wheelchair	60 (49)	7 (32)	38 (93)	15 (25)
Electric wheelchair/scooter	18 (15)	15 (68)	2 (5)	1 (2)
Walking devices	15 (12)	0 (0)	1 (2)	14 (23)
No assistive devices	30 (24)	0 (0)	0 (0)	30 (50)

Outdoors<sup>1,2</sup>

Manual wheelchair	39 (32)	6 (27)	23 (56)	10 (17)
Electric wheelchair/scooter	51 (41)	16 (73)	18 (44)	17 (28)
Walking devices	18 (15)	0 (0)	0 (0)	18 (30)
No assistive devices	15 (12)	0 (0)	0 (0)	15 (25)

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AIS = American Spinal Injury Association (ASIA) Impairment Scale [32]; SD = standard deviation.

<sup>1</sup>Significant ( $p < 0.05$ ) differences between the paraplegia AIS A-C and the all AIS D.

<sup>2</sup>Significant ( $p < 0.05$ ) differences between the tetraplegia AIS A-C and the all AIS D.

<sup>3</sup>Significant ( $p < 0.05$ ) differences between the tetraplegia AIS A-C and the paraplegia AIS A-C.

<sup>4</sup>Traffic/transportation (motor vehicle, train, bicycle), fall, workplace accident, diving accident, gunshot/assault/torture, other traumatic (e.g., sports, leisure activities).

<sup>5</sup>Spinal tumour, spinal disk herniation, spinal arteriovenous malformation, spinal infarction, spinal infection.

<sup>6</sup>Living in a relationship (married/cohabiting/partner).

<sup>7</sup>Including personal assistance, home-help service, dependent on next-of-kin/significant other, personal security alarm, help with cleaning/household/maintenance, escort, other.