
**SURVIVAL AND LONG-TERM OUTCOMES
IN PERSONS WITH
TRAUMATIC SPINAL CORD INJURIES**

Doctoral thesis
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Sterkest er den person som heller vinner over seg selv enn over andre

**In memory of my dear, valiant father, Erik Heieren,
who has always served as the most important example to me.**

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ABSTRACT

Background: A spinal cord injury (SCI) causes an enormous change in a person's life. The physical and psychosocial adjustments post-injury are complex and extremely challenging, and there is a high risk of serious complications both in the acute phase and several years after the trauma. International literature shows that long-term survival in persons with traumatic SCI has increased significantly over the last 50-60 years. A marked improvement in the acute medical management as well as highly specialised SCI rehabilitation have contributed to changes in morbidity and mortality patterns in this group of patients.

Information on mortality and causes of death in the Norwegian SCI population is scarce. In addition, more knowledge is required about outcomes in persons surviving more than 20 years after the injury.

Objectives: To study persons with traumatic SCI admitted to Sunnaas Rehabilitation Hospital (SunRH) in 1961-1982 with focus on mortality, risk indicators for early death, and causes of death (paper I) and also long-term outcomes regarding health-related quality of life (HRQOL), health problems, employment, and life satisfaction (papers II-III). A further aim was to review and present data on employment in persons with SCI on the basis of international research (paper IV).

Material and Methods: A cross-sectional survey, partly with retrospective data. All patients who survived the first year after a traumatic SCI and who were admitted to the SunRH in 1961-1982 ($n = 387$) were included.

Paper I: Standard mortality ratios (SMRs) were estimated. SMR is the actual mortality in the observed population divided by the expected mortality in the general population occurring during the same time interval. Causes of death were obtained from Statistics Norway and compared with those in the normal population. Risk indicators of early death were calculated using a Cox proportional hazards regression model.

Paper II: HRQOL was assessed with the Norwegian version of the Short Form 36 Health Survey (SF-36). The results were compared with norm data. Differences in HRQOL between various subgroups were estimated.

Paper III: A multiple logistic regression model was used to identify predictors for obtaining work after injury. In a Cox proportional hazards regression model, we estimated factors influencing early retirement. Life satisfaction, measured by the Life Satisfaction Scale (LiSat-11), was studied in relation to employment status.

Paper IV: A systematic review of literature on return to work (RTW) issues in SCI samples was carried out.

Results: By 31 December 2002, 142 (37 %) of the 387 persons with SCI had died. The most common causes of death were pulmonary diseases, cardiovascular diseases, and diseases in the urinary tract. SMRs were 1.8 in men and 4.9 in women, 2.4 in tetraplegic men and 7.6 in tetraplegic women, 1.3 in paraplegic men and 3.3 in paraplegic women. If the SMR exceeds 1.0, the mortality rate in the studied sample is larger than in the general population; an SMR of 2.0 indicates twice as many deaths as expected. Cause-specific SMRs were markedly elevated for urogenital diseases, suicide, pneumonia/influenza, cancer in the urinary tract, and diseases of the digestive system. Indicators for early death were: higher age at

injury, tetraplegia versus paraplegia, functionally complete SCI versus a less severe injury, pre-injury cardiovascular disease, pre-injury alcohol/substance abuse, and pre-injury psychiatric disorder.

A total of 237 persons were asked for participation in the investigation on long-term consequences after SCI. The final study sample comprised 165 (135 men and 30 women) persons, 30 % with functionally complete tetraplegia and 55 % with functionally complete paraplegia. The most common injury aetiologies were transport accidents (53 %) and falls (19 %). HRQOL was lower in the SCI sample than in the normal population, and most impaired in persons reporting health problems (79 %). The most often reported main health problems were: 'pain', 'urogenital problems', 'my disability' and 'musculoskeletal problems'. A total of 107 (65 %) of the participants were employed at some time after the injury. The odds (odds ratios) of obtaining work post-injury were higher in persons of younger age at injury, in men, in paraplegic persons, and in persons with a less extensive SCI. Factors associated with a shorter interval from injury to termination of employment were higher age at injury, occurrence of injury after 1975 versus before, and pre-injury medical condition(s). Life satisfaction was better among people with current work.

The review study showed that low employment rates in individuals with SCI are reported. The most successful RTW is seen in persons injured at a younger age, in less severely injured, and in persons with higher functional independence. It has been shown that, on average, the interval between injury onset and RTW is relatively long, and that employment rates improve with years after injury. Frequently reported barriers to work are problems with transportation, health and physical limitations, lack of work experience, lack of sufficient education or training, physical or architectural barriers, discrimination by employers, and loss of benefits. There is a tendency for persons with SCI to discontinue working at a young age. There are special challenges related to education and employment possibilities in SCI populations in less industrialized countries.

Conclusions: This investigation has shown higher mortality rates in the Norwegian study population compared to the general Norwegian population. Cause-specific SMRs were most markedly elevated for urogenital diseases, suicide, and pneumonia/influenza. Estimated risk indicators for death suggest possibly preventable causes, such as co-morbidity and alcohol/substance abuse. In this group of long-term survivors after SCI, HRQOL was decreased, especially in persons with health concerns such as pain. The proportion of persons employed after injury decreased from 65 % to 35 % with time. Employment after SCI has been linked by many authors to better psychosocial and medical adjustment. Different interventions to help people obtain and maintain employment after injury are important.

NORWEGIAN SUMMARY

Bakgrunn: En ryggmargsskade (RMS) medfører en enorm omveltning i livet. Den fysiske og psykiske tilpasningen etter slik skade er spesielt kompleks og utfordrende. Det er stor risiko for alvorlige komplikasjoner i akuttfasen, men også mange år etter selve skaden. Internasjonal litteratur viser at langtidsoverlevelsen for personer med RMS har økt betydelig de siste 50-60 år. En stadig utvikling i akuttmedisinske metoder og spesialisert rehabilitering har bidratt til endrede sykkelighets- og dødelighetsmønstre i denne populasjonen. Det er tidligere gjort lite kartlegging av dødelighet og dødsårsaker blant norske personer med RMS. Dessuten har vi for lite kunnskap om det å leve mer enn 20 år med slik skade.

Hensikt: Å undersøke alle pasienter med traumatisk RMS innlagt i Sunnaas sykehus HF i perioden 1961-1982 med henblikk på: (*artikkel I*) overlevelse/dødelighet, risikofaktorer for tidlig død, og dødsårsaker, og (*artiklene II-III*) helserelatert livskvalitet, helseproblemer, arbeidssituasjonen og tilfredshet med livet blant personer som har levd mer enn 20 år med RMS. Et videre formål var å skrive en oversiktsartikkel (*artikkel IV*) basert på internasjonal litteratur om sysselsetting og arbeid blant personer med RMS.

Materiale og metode: En tverrsnittundersøkelse med retrospektive data. Alle pasienter som overlevde det første året etter en traumatisk RMS og som ble innlagt i Sunnaas sykehus HF i perioden 1961-1982 ($n = 387$), ble inkludert.

Artikkel I: Såkalte Standard mortalitets rater (SMR: Dødelighet i en utvalgt populasjon versus forventet dødelighet i normalbefolkningen i samme tidsperiode) ble estimert. Dødsårsaker ble innhentet fra Statistisk Sentralbyrå og sammenliknet med de i normal populasjonen. Risikofaktorer for tidlig død ble beregnet ved hjelp av en Cox proporsjonal regresjons modell.

Artikkel II: Helserelatert livskvalitet ble undersøkt ved hjelp av den norske versjonen av instrumentet Short Form-36 Health Survey (SF-36). Resultatene ble sammenliknet med normaldata, og vi så også på forskjeller i ulike undergrupper.

Artikkel III: Multippel logistisk regresjon ble brukt til å identifisere prediktorer for å erverve/ikke erverve jobb etter skade. Ved hjelp av en Cox proporsjonal regresjonsmodell beregnet vi faktorer med innflytelse på tid fra skade til tidspunktet man eventuelt sluttet å jobbe. Vi sammenliknet også selvrapportert "tilfredshet med livet" mellom personer som var i arbeid og de som ikke var i arbeid på studietidspunktet.

Artikkel IV: Systematiske søk og gjennomgang av internasjonal litteratur som omhandler personer med RMS og deres arbeidsliv.

Resultater: Pr. 31.12.2002 var 142 (37 %) personer med RMS døde. De vanligste dødsårsaker var lungelidelser, hjerte/- karsykdom og sykdom i urinveier. Mortalitetensratene viste en overdødelighet blant personer med RMS sammenliknet med normalbefolkningen: SMR var 1.8 for menn og 4.9 for kvinner, 2.4 for menn med tetraplegi og 7.6 for kvinner med tetraplegi, 1.3 for menn med paraplegi og 3.3 for kvinner med paraplegi. Dersom SMR overstiger 1.0 er dødeligheten i

studiepopulasjonen høyere enn i den generelle befolkningen; når SMR er 2.0 er dødeligheten dobbelt så stor som forventet. SMR var også betydelig økt for følgende dødsårsaker: urogenitale lidelser, selvmord, lungebetennelse/influensa, kreft i urinveier, og for sykdom i mage/-tarm systemet. Indikatorer for tidlig død var: høy alder på skadetidspunktet, tetraplegi, komplett RMS, hjerte/-karsykdom før RMS, alkohol/rusmisbruk før RMS, og psykiatrisk diagnose før RMS.

I alt 237 personer ble forespurt om å delta i en kartleggingsstudie med fokus på langtidsfølger etter RMS. Totalt deltok 165 personer (135 menn og 30 kvinner); av disse hadde 30 % komplett tetraplegi og 55 % komplett paraplegi. De vanligste skadeårsaker var transportulykker (53 %) og fallulykker (19 %). Helserelatert livskvalitet var lavere i RMS-populasjonen enn i normalbefolkningen, og den var spesielt lav hos de med rapporterte helseplager (79 %). De vanligste helseplagene var “smerter”, “komplikasjoner relatert til urinveier”, “selve ryggmargsskaden”, og “muskel/-skjelett plager”. Totalt 107 personer (65 %) kom i jobb etter ulykken. Sjansen (odds ratio) for å komme tilbake i arbeid var større for yngre personer, for menn, for de med paraplegi, og for personer med mindre omfattende RMS. Faktorer forbundet med kort yrkesliv var høy alder ved skade, skadedato etter 1975, og sykdom før man pådro seg RMS. Tilfredshet med livet var best blant personer som fortsatt var i jobb på studietidspunktet.

Oversiktsartikkelen viser at en høy andel av ryggmargsskadde ikke er i jobb. Det å komme i jobb etter skaden synes å være vanligst blant personer som er yngre på skadetidspunktet, de med mindre skadeomfang, og de med høyere grad av fysisk selvhjelpenhet. Det gjennomsnittlige tidsintervallet fra skade til jobb er relativt langt, og andel personer i jobb øker med tid (år) etter skade. Hyppig rapporterte barrierer som vanskeliggjør jobb er: problemer med transport, helse og fysiske begrensninger, manglende arbeidserfaring, mangel på tilstrekkelig opplæring eller arbeidstrening, fysiske eller arkitektoniske barrierer, diskriminering på arbeidsplass, og tap av ulike “goder”. En tendens er at personer med RMS slutter i arbeid i ung alder. Det er ulike utfordringer knyttet til sysselsetting i RMS populasjoner fra land til land, spesielt vanskelig i utviklingsland.

Konklusjon: Undersøkelsen har vist overdødelighet i en norsk ryggmargsskadepopulasjon sammenliknet med normalbefolkningen, og også en spesiell høy forekomst av dødsårsaker relaterte til urinveier, selvmord, og lungebetennelse/influensa. Særlig viktige er funnene som indikerer potensielt forebyggbare faktorer (helse og rusproblematikk) for tidlig død. Studien viste at helserelatert livskvalitet var redusert blant personer som har levd mer enn 20 år med RMS, og særlig hos de som rapporterte helseplager som for eksempel smerte. Deltakerne anga en prosentvis nedgang i sysselsetting, fra 65 % til 35 %, over tid. Studier fra andre land viser at sysselsetting blant personer med RMS er forbundet med bedre psykososial og medisinsk tilpasning. Det er viktig med ulike tiltak for å bedre sysselsetting blant personer med RMS, og også for å hindre at de trekker seg tidlig ut av jobb. Det er ulike utfordringer knyttet til sysselsetting i RMS populasjoner fra land til land, og spesielt vanskelig i land med lavere velferd.

LIST OF PUBLICATIONS

Paper I

Lidal IB, Snekkevik H, Aamodt G, Hjeltnes N, Stanghelle JK, Biering-Sørensen F.

Mortality after spinal cord injury in Norway.

Journal of Rehabilitation Medicine 2007; 39 (2): 145-51.

Paper II

Lidal IB, Veenstra M, Hjeltnes N, Biering-Sørensen F.

Health-related quality of life in persons with long-standing spinal cord injury.

Spinal Cord 2008; 46 (11): 710-5.

Erratum in: *Spinal Cord* 2008; 46 (11):765.

Paper III

Lidal IB, Røislien J, Hjeltnes N, Stanghelle JK,

Biering-Sørensen F.

Employment of persons with spinal cord lesions injured more than 20 years ago.

Disability and Rehabilitation 2009; 31 (26):2174-84.

[PubMed – in process]

Paper IV

Lidal IB, Huynh TK, Biering-Sørensen F.

Return to work following spinal cord injury: a review.

Disability and Rehabilitation 2007; 29 (17): 1341-75.

ABBREVIATIONS

AIC	Akaike's Information Criterion
AIS	ASIA Impairment Scale
AIS A	AIS grade A; see definition on page 21
AIS B	AIS grade B; see definition on page 21
AIS C	AIS grade C; see definition on page 21
AIS D	AIS grade D; see definition on page 21
AIS E	AIS grade E; see definition on page 21
ASIA	American Spinal Injury Association
BP	Bodily Pain (one out of eight domains in the SF-36)
C	Cervical
CI	Confidence interval
CVD	Cardiovascular disease
Def	Definition
DP	Disability pension
EGP	The Erikson Goldthorpe Portocarero social class scheme
ES	Effect size
Fig	Figure
GH	General Health (one out of eight domains in the SF-36)
HRQOL	Health-related quality of life
ICD	International Classification of Diseases
ICD-7-10	ICD – 7 th , 8 th , 9 th , and 10 th Edition Clinical Modification
ICF	International Classification of Functioning, Disability and Health
ICIDH	International Classification of Impairments, Disabilities and Handicaps
L	Lumbar
LiSat-11	Life Satisfaction Scale-11
MCS	Mental component score
MH	Mental Health (one out of eight domains in the SF-36)
MOS	Medical Outcomes Study
n	numbers/sample size
OR	Odds ratio
PCS	Physical component score
PF	Physical Functioning (one out of eight domains in the SF-36)

QOL	Quality of life
RE	Role Emotional (one out of eight domains in the SF-36)
RP	Role Physical (one out of eight domains in the SF-36)
RR	Relative risk
RTW	Return to work
S	Sacral
SCI	Spinal cord injury
SD	Standard deviation
SF	Social Functioning (one out of eight domains in the SF-36)
SF-36	The Short Form 36 Health Survey
SMR	Standardised mortality ratios (the actual mortality in an observed population divided by the expected mortality in the general population occurring during the same time interval)
SPSS	Statistical Package for the Social Sciences
SunRH	Sunnaas Rehabilitation Hospital
Th	Thoracic
VT	Vitality (one out of eight domains in the SF-36)
WHO	World Health Organization
WHOQOL	World Health Organization Quality of Life assessment group

1. INTRODUCTION

'Disabled is not something that we are but that we become as a result of society's lack of respect for diversity. Disability is not a characteristic of the individual, but an attitude and physical barriers that prevents people with impairments from participating on the same level as others in our society'(1).

1.1. Background

Sixty to seventy years ago the general prognosis for persons with spinal cord injury (SCI) was poor. The immediate survival after the injury was short, and the one year survival rates were low as a result of medical complications such as renal failure and pulmonary infections (2-8). However, in 1954 Donald Munroe pointed out that the outlook for these patients was becoming more optimistic, and he was particularly focused on the possibilities of making persons with SCI ambulatory and capable of working (9). He stressed the importance of an active social life, and stated that persons 'with full self-care ability should be able and should be expected to go to work'. Since then, advances in emergency medical techniques, acute care and rehabilitation of SCI have resulted in considerably improved longevity in this group, and an increased interest in long-term outcomes on morbidity, mortality and quality of life (QOL) has developed.

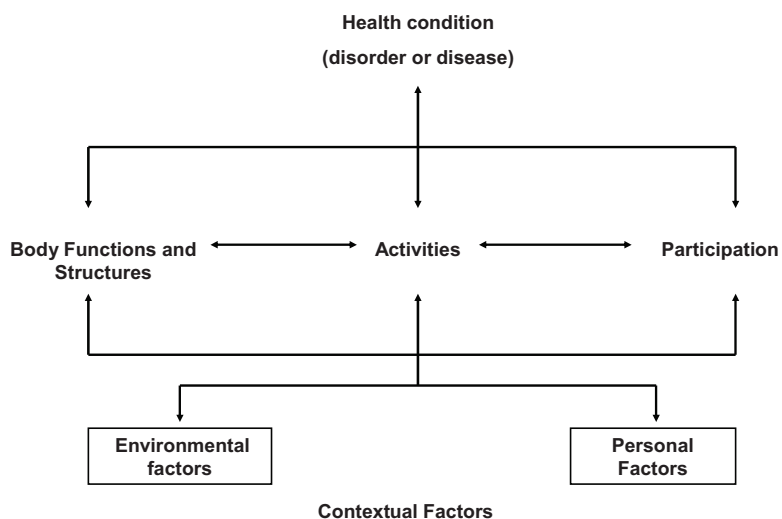
There has been marked progress in the conceptualisation of disability since the World Health Organisation (WHO) introduced an expanded definition of health in 1948, according to which 'Health is a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity' (10). In 1980 the International Classification of Impairments, Disabilities and Handicaps (ICIDH) was published, and this suggested conceptual distinctions between three levels of disablement-affected performance. In 2001, a revision of the ICIDH was published as the International Classification of Functioning, Disability and Health (ICF) (11). Munroe, ahead of his time, called attention to rehabilitation goals that involve

participation activities (9). Some of the same ideas have subsequently formed the basis of the ICF. In its description of health, the ICF includes the aspect ‘participation in activities’ (11;12).

Enhancement of daily functioning, well-being, and participation are important goals in the treatment and rehabilitation of persons with SCI. In ICF, the term ‘handicapped’ was replaced by the term ‘participation’, hence emphasising the personal involvement in a life situation. Participation refers more to the personal fulfilment of roles than to fulfilling roles deemed important by the society. The ICF also acknowledges the significance of contextual factors, specifically personal factors and environmental factors, which can have an impact on the individual and the individual’s state of health (Fig. 1). Further, according to the WHO, ‘A diagnosis alone does not predict service needs, length of hospitalization, level of care, or functional outcomes. Nor is the presence of a disease or disorder an accurate predictor of receipt of disability benefits, work performance, return to work potential, or likelihood of social integration’ (12).

Figure 1:

International Classification of Functioning, Disability and Health (ICF)



Rehabilitation after SCI is a lifelong process (13). It involves training the person with disability to achieve his maximum potential for normal living physically, psychologically, socially, and vocationally – a process that starts at the time of injury and continues for the remainder of the person’s life (13). In Norway today, persons with SCI are treated in one of three highly specialised ‘Spinal units’, located in three places in Norway (Haukeland University Hospital in Bergen, St. Olav University Hospital in Trondheim, and Oslo University Hospital/Sunnaas Rehabilitation Hospital (SunRH)). In comparisons with other Nordic countries, studies of the epidemiology of SCI including long-term outcomes on survival and challenges facing persons years after the injury have been limited in Norway. However, Gjone & Nordlie studied the incidence of traumatic SCI in 1974/1975 (14), and in 1980 McAdam & Natvig published results from a 16-year follow-up of ambulation outcomes and vocational rehabilitation (15). More recently (in 2001, 2005 and 2009), Hagen et al studied: 1) the causes and levels of SCI in persons admitted to the Haukeland University Hospital in Bergen (16); 2) elderly persons who sustained a traumatic SCI (17); 3) the incidence and the prevalence of SCI in Western Norway (18); and 4) mortality and causes of death after traumatic SCI in a geographical cohort (19).

In Denmark, a number of studies on the epidemiology of SCI and long-term outcomes after such injuries have been conducted (20-27). Recently, Finnish investigators have presented incidence results of SCI based on national Finnish data, as well as prevalence data from Helsinki, and further results from studies on life situations, employment outcomes and health-related quality of life (HRQOL) in SCI patients (28-32). In Sweden, the situation of persons with SCI in the Stockholm area has been described in several reports (33-38), and among other studies from Sweden are more reports focusing on quality of life and on mental health in persons with SCI (39;40).

1.2. Traumatic spinal cord injury (SCI)

Definitions of spinal cord injury

An SCI affects conduction of sensory and motor signals across the site(s) of lesion(s), and thus represents impairment or loss of motor and/or sensory function secondary to damage of neural elements within the spinal canal (41). The results of an SCI depend on the level and the extent of the lesion (41). The consequences of a cervical SCI consist of impairment of function in all four extremities, the trunk and pelvic organs (tetraplegia). In persons with a lesion below the cervical segments, i.e. in the thoracic (Th), lumbar (L) or sacral (S) segments, the impaired function may affect the trunk, the lower extremities and the pelvic organs depending on the level of injury (paraplegia). Injuries involving the conus medullaris or the cauda equina are usually merged into the ‘paraplegia’ group (41).

Classification of SCI

In the 1970s, HL Frankel presented a system for classifying SCI (42). This system contained five categories, i.e. no function (A), sensory only (B), some sensory and motor preservation (C), useful motor function (D), and normal function (E) below injury level. In 1992 the Frankel classification was modified by the American Spinal Injury Association (ASIA), and the International Standards for Neurological Classification of Spinal Cord Injury was then introduced, i.e. the ASIA Impairment Scale (AIS); last revision in 2003 (41). Briefly, the AIS system is as follows:

- *AIS-A* – Complete: No sensory or motor function is preserved in the sacral (S) segments S4-S5.
- *AIS-B* – Incomplete: Sensory, but not motor function is preserved below the neurological level and includes the sacral segments S4-S5.
- *AIS-C* – Incomplete: Motor function is preserved below the neurological level, and more than half of key muscles below the neurological level have a muscle grade less than 3 (Grades 0-2) (3 = Movement against gravity but not against resistance)
- *AIS-D* – Incomplete: Motor function is preserved below the neurological level, and at least half of the key muscles below the neurological level have a muscle grade of 3 or more.
- *AIS-E* – Normal: Sensory and motor functions are normal.

Sacral functioning implies physiological continuity of spinal cord long tract fibres with the sacral fibres located more at the periphery of the cord. The presence of sacral fibres is important when defining the completeness of the SCI and the potential for some motor recovery.

The neurological level of injury is the most caudal level at which both motor and sensory levels are intact (41). The motor level is defined by the most caudal key muscles that have muscle strength grade 3 or above while the segment above is normal (41). The sensory level is defined as the most caudal dermatome with a normal sensory function (41).

Aetiology of SCI

Depending on the cause of the SCI, the lesion is classified as either *traumatic* or *non-traumatic*. Using the International Spinal Cord Injury Core Data Set (43), the aetiology is classified as follows: 1) sports and leisure activities, 2) assaults, 3) transport activities, 4) falls, 5) other traumatic causes, 6) non-traumatic causes, 9) unknown. An injury event might be classifiable into more than one of these categories, and a system of prioritisation for traumatic causes has therefore been developed: The first coding priority is given to sports, then to assaults, next transport and so on (43).

Incidence and prevalence of SCI in Norway

Gjone & Nordlie studied the incidence of SCI throughout Norway in 1974 and 1975, and reported that 65 and 66 persons with traumatic SCI, including cauda equina lesions, were admitted to Norwegian hospitals during this two-year period (14). In 2009, a 50-year follow-up study on the incidence of traumatic SCI estimated the crude prevalence rate of traumatic SCI in two Norwegian counties to be 36.5 per 100 000 inhabitants (18). The authors indicated a tendency of an increase in the incidence of traumatic SCI during the 50 year period.

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In the present research much attention has been devoted to long-term outcomes after traumatic SCI, and especially to survival and causes of death, health-related quality of life, perceived health problems, work participation, and life satisfaction in the target group.

The next sections are focused on background information on these topics, and are presented in the same order in which they appear in the papers.

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1.3. Selected long-term outcomes after traumatic SCI

The literature provides increasing information on long-term outcomes after traumatic SCI. There is no doubt that medical advances and highly specialised care after SCI have contributed to changes in the morbidity patterns, longevity, and causes of death in the target group, particularly in the more wealthy part of the world (44). However, improvement of long-term outcomes is not solely dependent on advances in medicine, but may also result from new knowledge acquired from epidemiological research (45;46). Concerning research in the rehabilitation field, mortality as well as employment and quality of life are recognised as ‘strong endpoints’ (47).

Survival, risk indicators of death, and causes of death in SCI

Trends in survival after SCI

According to international literature, persons with SCI have a diminished life expectancy compared with able-bodied persons (2;8;20;45;48). However, over the past decades, several studies have documented improved survival rates among persons who have sustained a spinal cord lesion (2;20;44;48-52). In Denmark, a significant decrease in the overall mortality was observed in the period 1972–1992 compared with 1953–1973, and the authors showed that the gap in survival probability between the normal population and the SCI sample was considerably diminished from the 1950s and 1960s to the 1970s and 1980s. In 2007, DeVivo calculated that since 2002 the odds of dying during the first post-injury year were only 44 % as high as they were during 1973–1981 (44). It was also stated that in the case of a 20-year-old male who sustained a complete (AIS A) tetraplegia/C5 injury due to a motor vehicle crash and who was not ventilator-dependent, his life expectancy would be 33.8 years in 1976 and 36.9 years in 2006 on the first anniversary of injury. However, DeVivo concluded that while the first year mortality rates after SCI improved in subsequent years, the longer-term mortality rates

showed no improvement since 1982 (44). Krause et al also reported that the mortality within the first year post-injury seemed to decrease, but that the long-term survival rates appeared to have plateaued (46;49). In conclusion, longer-term improvements are less clear than those of the first year after SCI (52).

Until recently, relatively little was known about survival after SCI in Norway. The newly published study on mortality in an unselected, geographically defined cohort of patients with traumatic SCI from Western Norway showed increased Standardised mortality ratios (SMRs), especially in women, in persons with complete lesions, and in persons with cervical level of injury (19). However, the SMRs showed no change over time.

Risk indicators of mortality in SCI

Several authors have documented demographic, psychosocial and SCI-specific risk indicators for death. There is substantial evidence that excess mortality is attributed to higher age at injury, neurological level and completeness of the lesion (2;8;20;48;51;53-55). Concerning gender, the picture has been somewhat mixed, but most studies have shown higher mortality in men than in women (2;49). Employment status has also been related to mortality (56). Additionally, recent studies have found that much of the excess mortality in chronic SCI is related to potentially treatable factors such as cardiovascular diseases (CVD), diabetes, and lung diseases, as well as smoking and other behavioural risk factors (45;46). In 2009 a study also identified psychological risk factors in relation to mortality after SCI (57). Krause & Carter stated that ‘health and secondary condition variables most directly contribute to mortality and are themselves predicted by health behaviours, which are in turn predicted by psychological and environmental factors’ (57). Studies of risk indicators of mortality are necessary to improve the overall health and longevity of people with SCI. Since long-term mortality rates seem to have shown little improvement in the past two decades, it is

considered more important than ever to understand the broad range of factors that contribute to early death after SCI (58).

Causes of death in SCI

International studies have proven that changes in causes of death patterns in SCI populations have taken place over time (6;8;59). In Denmark, for example, a decrease in SMRs for most causes of death was found when comparing two periods (20). From other studies, it seems as if the cause-specific mortality rates attributable to urinary tract complications have diminished (8;49;60;61), and that heart disease and respiratory complications have become the leading causes of deaths in SCI populations in recent years (8;20;45;49;59). The focus on management of bladder functioning and also better medications for all kinds of infectious diseases have contributed most importantly to the improved survival rates and the decrease in deaths from urinary tract complications. Nevertheless, another concern is that the rates of suicide seem to have risen (20;61;62).

Although the literature provides a fair amount of information on causes of death after SCI, acquisition of more knowledge will help to guide decisions in medical management and lead to appropriate preventive strategies.

In most countries the ‘underlying cause of death’ forms a basis for the official cause of death statistics. DeVivo et al passed criticism on the procedures in cause of death determination and reporting, on basis of a high number of deaths in persons with SCI attributed to unspecified cardiac arrests and ill-defined conditions. The authors underlined that to attribute cause of death on death certificates to ‘spinal cord injury’ or to the original event that caused the injury without identifying the secondary complications that actually caused death, is not useful (59).

Health-related quality of life

Measures of quality of life have increasingly become a key concept in research and clinical services (63). QOL has been defined as a multi-dimensional construct that includes physical functioning, functional ability, emotional functioning, and satisfaction with life (64). The WHO Quality of Life assessment group (WHOQOL) defines QOL as ‘The individual’s perception of their position in life in the context of the culture and value system in which they live and in relation to goals, expectations, standards and concerns’ (65). Various approaches to quantification of QOL have been developed, depending on whether the focus is meant to be HRQOL, well-being, or QOL as a superordinate construct (66-68).

HRQOL can be distinguished from QOL in that it primarily concerns those factors that fall under the purview of health care providers and health care systems (69). There is no agreement on one single definition of HRQOL (70), but general measurements of HRQOL focus on the individual’s satisfaction or happiness with domains in life that are affected by health or health care. HRQOL is a dynamic phenomenon, influenced by changes in an individual’s life and in the society and the world at large, including changes in achievements, statuses, and the environment (66).

In the last two decades there has been a large increase in the number of studies that assess HRQOL among persons with SCI. Studies of persons with SCI in Canada, USA, Sweden and Australia have shown significant reductions in HRQOL compared to general populations (36;40;71-73). The largest difference has been found in physical functioning (PF), whereas scores on mental health (MH) and social functioning (SF) have diverged less from general population scores (40;73). Previous studies have also shown that older age, unemployment, hospitalisation during the last year, and various medical complications such as pain, spasticity, and incontinence seem to have more negative effects on HRQOL than the level and extent of SCI as such (36;71).

Quality of life is a fundamental issue for persons with SCI; for some patients, living longer may not necessarily mean living better. It has been underlined that the question of HRQOL in persons with SCI needs to be addressed in different countries, and that factors that might influence HRQOL should receive greater attention (72;74).

‘Health problems’ in persons with chronic SCI

Persons with spinal cord lesions are confronted with various problems related to *associated conditions* or to *secondary conditions*, even many years post-injury (8;27;32-34;75-83). These conditions may interfere with their physical, mental and/or social well-being, and often lead to rehospitalisations (84;85). An associated condition is seen as part of the primary pathology, such as neurogenic bowel and bladder function, and spasticity (81). Secondary conditions are preventable and occur at higher rates among persons with SCI than in the general population. Spinal cord injured persons are at risk of developing secondary conditions, such as pressure ulcers or musculoskeletal pain due to upper-extremity overuse (80;81;83;86). With progression, secondary conditions can increase the severity of the disability, decrease the quality of life and cause unemployment. Further, it is important to remember that some of these conditions may become serious and even lead to death (84;87).

Concerning pressure sores, these are described in many reports as the most frequent complications, and there has been a trend towards an increasing number of people developing sores with increasing time post-injury (8;76;83;88). Urinary tract infections are still a frequently reported health problem in persons with SCI (8;76-78;84). The prevalence of pain is also high, and pain has been described as the most disabling condition, both for daily and social activities (34;76;80). In addition to the physical problems in SCI exemplified above, difficulties in daily living and psychosocial problems usually affect the health status.

'Health' is a multidimensional construct including physical, mental, and social aspects, which together are commonly referred to as the 'Health Triangle'. Persons with physical disabilities are as able to be healthy as able-bodied persons (13). 'Perceived health status' or health perceptions are subjective ratings by the individual in question regarding his health status. Some people perceive themselves as healthy even when suffering from one or more chronic diseases, while others perceive themselves as ill when no objective evidence of disease can be found (69).

Research is needed to improve prevention and treatment strategies of common secondary conditions and symptoms and to evaluate the need for health care programs/service planning.

Employment

The involvement in activities seems to be strongly related to health and well being (89). One of the most important 'participation activities' in adults is the involvement in productive work (90). Most societies expect people to work, and being employed is deemed to be a key indicator to community integration in the Western society. New incidents of traumatic SCI often befall young adults, and improvement of the employment situation after injury is therefore of particular importance (13).

Work after SCI has received much attention because of the psychological, social, financial, and political implications (37;91;92). Despite evidence that return to work (RTW) is associated with a better quality of life, higher grade of participation, and increased physical and psychological well-being (93-95), research has consistently revealed low employment rates after injury, a number of barriers to work in people with disabilities, and a tendency for people with SCI to have reduced working lives (96;97). Nevertheless, it has been shown that longer duration of the SCI is associated with higher employment rates (98-102).

To study and compare employment outcomes in SCI require a careful approach, especially to the definition of the term ‘employed’ (103). Different national (un)employment situations and policies also need to be considered. The prerequisites for obtaining work differ internationally and are influenced by the social policies of each country, including disability compensation systems, as well as by the level of unemployment (104). For an elaboration of these aspects, see the discussion section of paper III.

In the 1960s and 1970s, McAdam & Natvig studied vocational rehabilitation in Norwegian persons with complete paraplegia (15). The authors reported that 59 % were working for their ‘living’. They underlined the difficulty in comparing results with others, as populations vary in respect to demographic characteristics as well as to level and type of SCI. The influence of medical problems on the outcomes regarding vocational rehabilitation was also commented on. In Sweden, the results from the Stockholm Spinal Cord Injury Study (1996) showed that less than half of the participants were gainfully employed (37), and it was also reported on a relative lack of financial reserves in this population. Approximately the same employment rate was found in the area of Gothenburg in 2006 (105).

Life satisfaction

‘Life satisfaction’ is a measure of an individual’s perceived level of well-being and happiness; a subjective component of QOL (66). The cognitive subjective process by which an individual evaluates his overall satisfaction with his current life status in comparison with self-defined expectations of how he would like his life to be, is among the descriptions of the term ‘life satisfaction’ (106). A definition of ‘satisfaction with life as a whole’ was introduced by Fugl-Meyer et al, i.e. a person’s experience of life satisfaction reflects the extent to which the person achieves his vital goals (107).

The multiplicity of changes in a person’s physical being, self-esteem and life circumstances after SCI would be expected to influence his life satisfaction.

Although the results of different studies are not fully consistent, there are indications that life satisfaction appears to improve with age and duration of injury (88;108). Putzke et al concluded from their study that the level of life satisfaction during the first year of injury remained largely the same over the subsequent four years (109). However, Charlifue et al documented that life satisfaction improved with years post-injury (88). Another study indicated that persons with a higher education, a longer time since the injury, and who were currently employed, tended to report markedly higher life satisfaction (93). Among factors that have been associated with lower overall life satisfaction are unemployment, pain or/and having a poor perceived health, decreased mobility, and social integration (95;110). Krause & Broderic studied effects of ageing among persons with SCI over a 25-year period, and concluded that there were differences in the way the participants' lives changed over time, with both improvements and deteriorations (100). They showed that employment outcomes improved, as well as self-rated adjustment, but that satisfaction with social life, sex life and health diminished. With time, most people with SCI seem to 'adjust' to their new body and the lifestyle it imposes (36). The effect of response shift (adaptation or habituation) probably influences the perception of burden and coping perspectives. Through the years after the injury, most people with SCI face additional challenges that require new adaptations and coping. Enhancement of daily functioning and well-being are important goals in the lifelong treatment of persons with SCI.

1.4. Review of literature

Previous review studies of 'employment' in the SCI field reported that RTW rates ranged from 13 % to 48 % (Trieschmann, 1988) (13), and from 11 % to 69 % 1976-1992 (Athanasou et al, 1995; an original study with review data presented in the article) (111). Yasuda et al (2002) reviewed recent literature on RTW in persons with SCI, and concluded that 'successful RTW following

SCI is a complex interplay of injury severity, social and demographic issues, work conditions, and individual skills and motivation' (112). In 2009, Young & Murphy studied the literature on employment status after SCI carried out during the years 1992-2005 (103). On basis of their review it was concluded that approximately 40 % of working age people more than one year post-injury are employed at the time of data collection, with rates peaking at 10-12 years post-injury.

'Healthcare providers, consumers, researchers, and policy makers are inundated with unmanageable amounts of information, including evidence from healthcare research' (113). The growing literature on rehabilitation makes reviews indispensable. Reviews play a crucial role in summarising and synthesising the knowledge base (114). Three different approaches to the review of literature are: meta-analyses, systematic reviews, and narrative reviews.

A meta-analysis is a statistical technique for amalgamating, summarising and reviewing quantitative research. It combines the results of several studies that address a set of related research hypotheses. Selected parts of the results from the studies included are entered into a database and then 'meta-analysed'. A meta-analysis can be considered to be original statistical research. Findings from a meta-analysis are reported in terms of effect-sizes (ESs).

Narrative reviews generally are comprehensive and cover a wide range of issues within a given topic. Typical narrative reviews do not reveal how the decisions were made about the relevance or the validity of the studies included (115).

A systematic review is a review article based on findings in original research studies on a specific topic. Articles that are selected and included in a review paper should be critically evaluated and interpreted. A systematic review involves balanced assessment of original research studies.

When preparing and planning a systematic review, it is of great value to follow steps recommended on 'how to write a systematic review' (113;116).

2. AIMS OF THE STUDY

The purposes of this doctoral research were:

1. To study the survival, mortality, risk indicators and causes of death in persons who survived at least one year after having sustained a traumatic SCI in the years 1961-1982.
2. To study persons who had sustained a traumatic SCI more than 20 years previously in order to evaluate their current HRQOL and perceived health problems, to identify factors influencing their employment situation, and to assess their life satisfaction.
3. To review employment data concerning persons with SCI in different countries.

The aim of the study was to collect the information mentioned above with the aim of increasing our knowledge and elucidating challenges concerning the situation in persons with long-standing SCI in Norway.

The data and the results summarised in this thesis are mainly of a descriptive character.

The specific research questions were as follows:

- What are the long-term mortality rates in a Norwegian sample of persons with traumatic SCI, and what are their most frequent causes of death? (Study I, paper I)
- To what degree do the mortality rates and the causes of death among persons with traumatic SCI differ from those in the general population in Norway? (Study I, paper I)
- What factors are indicating a higher risk of early mortality in persons with traumatic SCI? (Study I, paper I)

- What are the levels of HRQOL in persons with long-standing SCI? To what extent does their HRQOL differ from that in the general Norwegian population? (Study II, paper II)
- What are the most common health concerns among Norwegian persons who sustained a traumatic SCI more than 20 years ago? (Study II, paper II)
- To what extent do persons with SCI obtain and maintain work post-injury in Norway? What factors influence return to work and early retirement after SCI? (Study III, paper III)
- What are the levels of life satisfaction in the study population, and is there a difference in this respect between employed and unemployed persons? (Study III, paper III)
- What are the RTW rates and what are the employment situations after traumatic SCI in different countries? (Study IV, paper IV)
- What factors have been found to affect RTW positively and what factors have been found to influence RTW negatively? (Study IV, paper IV)

3. METHODOLOGY

3.1. Study design

- Studies I-III were observational. They were based on investigation of persons who sustained SCI 1961-1982. Study I had a cross-sectional design, exploring mortality rates, survival times and causes of death data up to a certain date, namely 31 December 2002. Retrospective data were also included. Studies II and III also had a cross-sectional design, as all participants were investigated at one point in time after injury. Some retrospective data were used in these studies.
- The review (study IV) was based on a systematic survey of research on employment in persons with SCI, covering the time period 2000-2006.

3.2. Study population and controls

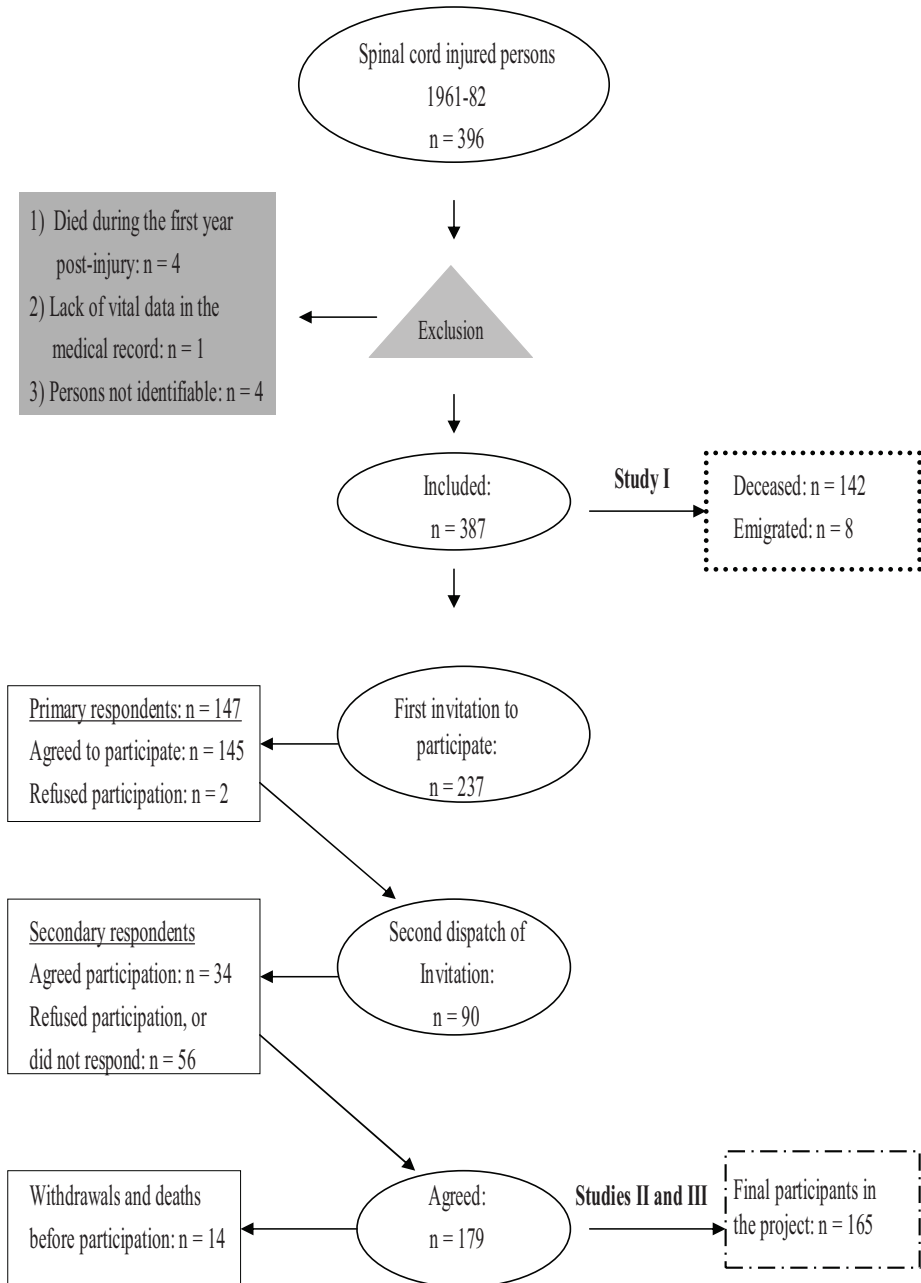
Study population

All persons ($n = 396$) who sustained a traumatic SCI and were admitted for rehabilitation at SunRH between 1961 and 1982, were considered for inclusion in studies I-III (Fig. 2). Thus, in all persons enrolled at least 20 years had elapsed since the injury when the studies were performed. Excluded were: 1) four patients who had died within the first year after the injury, 2) one patient who was omitted because of lack of data, and 3) four patients who could not be identified. The remaining 387 persons (321 men and 66 women) were initially included in the study material.

General population controls

For the study on mortality (study I), we obtained vital data for the general population, as well as the underlying causes of death in Norwegian men and women through the years 1961-2002 inclusive (Statistics Norway). For the study on HRQOL (study II), we obtained SF-36 norm data for 5,152

Figure 2. Overview of the inclusion process



persons from the Norwegian Survey Archive, Norwegian Social Science Data Services (117). Information on employment in the general population in 2004 was collected from Statistics Norway (study III).

3.3. Data collection

Medical records were reviewed with the aim of finding all patients who met the inclusion criteria, which were: 1) traumatic SCI; 2) survival at least one year post-injury; and 3) rehabilitation at SunRH 1961–1982. Demographic and injury-related data were then extracted from the medical records (Table I). Information on vital (mortality) status and dates of death were collected from the Central Population Register of Norway, as also were the postal addresses of persons still alive. Dates of death up to 31 December 2002 were derived. The vital status of eight persons who had emigrated from Norway could not be determined, and these persons were therefore censored at their last known date alive (118).

Deceased persons

For each deceased study person with SCI, both the ‘underlying cause of death’ and the ‘immediate cause of death’ were collected from the Cause of Death Register and from death certificates, respectively. ICD-9 was used to classify diseases causing death, and deaths classified according to ICD-7, ICD-8 and ICD-10 editions were translated to ICD-9.

The underlying cause of death is the cause that is usually applied in international cause of death statistics (i.e. listed in the Cause of Death Register) (119-121). The underlying cause of death forms a basis for the official statistics. When coding the underlying cause of death according to the ICD (WHO) guidelines, certain criteria have to be fulfilled (121;122). One criterion is that more prominence is placed on the external cause of the injury-producing event, i.e. in many cases the injuries that caused the SCIs, than to

the immediate causes of death (48;59;121). In other words: the injury that caused the SCI many years before death occurred, was registered in the Cause of Death Register as the underlying cause of death in many cases (59). For this reason, we recoded in cases where the injury-producing event was listed as the underlying cause of death. In these situations, we extracted information from death certificates and used the next cause listed. However, in cases where an accident occurred subsequent to the SCI, the underlying cause of death remained coded as 'Unintentional injury'.

Long-term survivors

Two hundred and thirty-seven persons were contacted by postal mail, with a reminder if necessary, to recruit them for participation in the study. For those who agreed to participate, data collection took place as follows: A set of questionnaires for self-administration was mailed, together with a stamped return envelope and an appointment for a personal interview. A face-to-face interview and a clinical examination were then undertaken. Four persons were only interviewed by telephone. Another 21 persons were interviewed and examined in their respective homes. All interviews and examinations were conducted by the same person.

Non-respondents

In this doctoral investigation the term 'non-respondents' is used to cover all persons who either declined participation or did not respond to our enquiry. A study of the non-respondents was desired, in order to disclose any demographic (gender, age), injury-related (injury aetiology, level and extent of SCI) or pre-injury morbidity deviations from the participants. A further aim was to gather some information on the current health and employment status by a postal questionnaire. The existing Norwegian regulations, intended to protect the privacy of the individual, demand consent of each individual, both respondents and non-respondents, to use of any data from their medical

record (see also page 47). Hence, such a request was mailed to all non-respondents ($n = 58$) along with a brief questionnaire regarding their current health and employment status. From 35 of the 58 persons, a positive answer was received.

3.4. Variables and questionnaires used in the survey

In the next subsections, descriptions of relevant variables and specific instruments used will be presented. Table I lists the variables used in studies I-III.

Demographic and diagnostic items

The variables are listed in Table I. However, there is a need for some elaborations. For some of the analytical purposes we grouped variables into fewer categories, as follows:

Demographic variables

- 1) Age at injury was dichotomised into ≥ 21 versus < 21 years in study III.
- 2) Time since injury was divided into ≥ 27 versus < 27 years in study III.
- 3) Marital status was dichotomised into married/cohabitant versus single.
- 4) Occupational class was determined according to a modified version of the Erikson Goldthorpe Portocarero (EGP) social class scheme (123;124); this modified version includes ten categories. Retired persons were classified according to their former occupation. Persons of ages < 16 years were registered as 'under aged' in analyses that included occupational class.
- 5) Employment status was categorised into 'employed' (paid work) and 'not employed' (students, unemployed, homemakers). Persons of ages < 16 years at injury were recorded as 'under-aged' concerning employment status.
- 6) Region of residence at the time of injury was categorised into five groups (study I), and region of residence at the time of the survey was categorised into two groups: 'living in central eastern Norway (including Oslo)' versus 'other region of residence' (studies II and III).

Table I. Overview of variables and questionnaires used in studies I-III

Variables	Study I	Study II	Study III
Socio-demographic variables			
* Age at injury	X	X	X
* Age at time of survey		X	X
* Date of death if deceased (or censor)	X		
* Date of injury (and time since injury)	X	X	X
* Gender	X	X	X
* Vital status (alive/deceased)	X		
* Marital status at injury	X		X
Marital status at time of survey		X	
* Living alone at injury: yes/no	X		
* Occupational class at injury	X		X
* Employed/not employed at injury			X
† Employed/not employed at time of survey		X	X
* Region of residence at time of injury	X		
Region of residence at time of survey		X	X
Specific SCI characteristics			
* Injury aetiology (5 categories)	X	X	X
* Tetraplegia/paraplegia	X	X	X
Impairment group (4 categories)		X	X
* Frankel scores (A-C or D-E)	X	(X)	X
AIS scores (A-C or D-E)		X	
Selected variables possibly influencing rehabilitation			
* Associated injuries	X		X
* Pre-injury medical conditions or traumas	X		X
* Pre-injury alcohol or substance abuse	X		X
* Complications during initial rehabilitation	X		X
* Time period of injury: 1961-1975 or 1976-1982	X	X	X
* Working accident	X		
Other			
* Duration of rehabilitation (date of admission and discharge)	X		X
Data from Statistics Norway; Questionnaires			
Cause of death (ICD-9)	X		
LiSat-11			X
SF-36		X	
Self-reported main health problems		X	X
Questionnaire on employment (present employment status, work at anytime post-injury, time/age of possible retirement, work intensity)		X	X
Non-respondents questionnaire (n = 35)		X	X

* Data collected from the medical records.

† Collected from the questionnaire on employment.

AIS: ASIA Impairment Scale. DP: Disability pension.

LiSat-11: Life Satisfaction Scale-11. SMR: Standardised mortality ratios.

(x): Frankel scores used for comparison with non-respondents only.

Specific SCI characteristics

- 1) Injury aetiologies were grouped according to the International Spinal Cord Injury Core Data Set (see page 22). The categories ‘others’ and ‘unknown’ were put together because of few cases in each group (studies II and III).
- 2) Neurological levels of injury: tetraplegia and paraplegia (see page 20).
- 3) Frankel scores were merged into two groups: Frankel A-C and D-E to reflect functionally complete SCI and functionally incomplete SCI, respectively (see page 20).
- 4) AIS classes were merged into two groups: AIS A-C and D-E to reflect functionally complete SCI and functionally incomplete SCI, respectively.
- 5) Four impairment groups: tetraplegia AIS A-C, tetraplegia AIS D-E, paraplegia AIS A-C and paraplegia AIS D-E.

Selected variables possibly influencing rehabilitation

- 1) Associated injuries caused by the accident were merged into ‘present’/‘absent’.
- 2) Pre-injury medical conditions were categorised into groups referring to the most frequent diagnoses (‘respiratory disease’; ‘CVD’; ‘psychiatric diagnosis’, ‘other’) in study I, and as ‘present’/‘absent’ in study III.
- 3) Occurrence of pre-injury alcohol or substance abuse: ‘present’/‘absent’.
- 4) Secondary medical complications during rehabilitation: ‘present’/‘absent’
- 5) The participants were dichotomised into two incidence groups according to the time of injury, 1961-1975 and 1976-1982.

Short Form 36 (SF-36)

The 36-Item Short-Form Health Status Survey (SF-36) of the Medical Outcomes Study (MOS) is the most widely used generic HRQOL outcome measure (64;125-127). The SF-36 has been shown to be valid and reliable (126;128;129), and has been translated into many languages, including Norwegian (130). Normative values for this self-report health questionnaire have been published for the Norwegian population (131). Therefore, in this

study HRQOL was assessed using the Norwegian SF-36 (version 1.2, chronic). In 2002 the SCI Consensus Group suggested the use of SF-36 to measure HRQOL in chronic SCI (70).

The SF-36 contains one multi-item scale that assesses eight health concepts: ten questions concerning limitation of physical functioning because of health problems (PF); four questions concerning limitation in usual activities because of physical health problems (RP); two questions on bodily pain (BP); five questions concerning general health perception (GH); four questions on vitality (energy and fatigue) (VT); two questions concerning limitation of social functioning because of physical or emotional problems (SF); three questions on limitation in usual activities because of emotional problems (RE); five questions concerning general mental health (psychological distress and well-being) (MH); and also one single-item measure of health transition. First, the raw scores were coded and recalibrated, and then the questions were summed and converted to eight scales (132). The scores range from 0-100 where higher scores indicate a better health status. The scales PF, RP BP and GH mainly measure physical components, while VT, MH, RE and SF measure mental health. The eight domains are often merged into two summary scales, the physical component score (PCS) and the mental component score (MCS). The summary scales were not carried out in this study.

Life satisfaction Scale 11 (LiSat-11)

Life satisfaction was assessed by the LiSat-11 containing 11 items: one question on satisfaction with life as a whole and ten questions on satisfaction within different life domains (107;133). The level of life satisfaction was described through a 6-grade scale ranked from 1 (very dissatisfying) to 6 (very satisfying). The LiSat-11 scale was dichotomised into satisfied (grades 5-6) and not satisfied (grades 1-4) as recommended by Fugl-Meyer et al (133;134). The LiSat-11 has shown satisfactory validity and reliability levels

(107). It has been used in SCI samples previously (135;136), and after reflection by the SCI Consensus Group, it was proposed that the LiSat-11 should be used to assess subjective quality of life in persons with SCI (64).

Questionnaire on employment situation

Long-term survivors who attended the study answered a checklist on their employment situation. The questionnaire was previously used at SunRH in a study of persons with multiple traumas (137). It contains six questions on both the pre-injury and the present occupational situation, two questions concerning changes in employment after SCI, two questions on disability benefits, and one question concerning the possible degree of current disability pension. In addition, we supplied with a question on time (year/age) of termination of work, and also a question on whether work was obtained at anytime after the injury. The questionnaire was answered twice by fourteen (9 %) respondents to allow on the reproducibility of the questionnaire to be checked.

Employment status was dichotomised into 'employed' and 'not employed'. Work intensity was dichotomised into 'full-time' or 'part-time'. Ever having worked since injury was categorised into 'yes' or 'no'.

Perceived health problems

We recorded health problems in a non-standard way by using an open-ended question on perceived main health problem(s); i.e. 'what would you say is your main health problem today'. In the event of more than one health problem, the participants were asked to list their problems as follows: main health problem, second worst problem, and so on. For analytical purposes, the perceived health problems were categorised into six groups, according to the frequency with which they were reported. The most often reported main health problems were: 'pain', 'urogenital problems', 'my disability', 'musculoskeletal problems', and 'other'. Additionally, several persons

reported to have ‘no health problem’. The subgroups ‘one health concern’ and ‘more health concerns’ were also established.

In paper II, the distributions of the perceived *main* health problems were presented, but data on the second or third worst health problems were not included. In paper III, the presented proportions on the three most frequently reported perceived health problems (‘pain’, ‘urogenital problems’, ‘my disability’) were thus somewhat higher than listed in paper II.

3.5. Statistical analyses, studies I-III

The algorithms in Statistical Packages for the Social Sciences (SPSS) versions 11.5 - 13.0 were used in most calculations. However, to the Cox proportional hazards regression analyses in study III, we used the R statistic software (<http://www.r-project.org>).

Throughout the present studies, the level of statistical significance was set at $p \leq 0.05$.

Descriptive statistics included: proportions, medians, ranges, means, and standard deviations (SD), and were used to characterise the study sample(s). Groups were compared with the independent *t*-test or the Mann-Whitney test for continuous data, and the Chi squared test or Fisher’s exact test for categorical outcome variables.

Standardised mortality ratios were computed for gender, tetraplegia/ paraplegia and two incidence periods (1961-1975 and 1976-1982). In addition, SMRs for selected causes of death were calculated. The expected numbers of deaths were estimated using age-gender-specific rates for the selected diagnoses.

To explore risk indicators for death, a Cox proportional hazards regression model (forward selection procedure) was used. Kaplan-Meier curves were applied: 1) to visualise survival by age at death or censoring of the SCI

population compared with the general population, and 2) to illustrate the length of time from injury until death or censoring in two incidence periods. A Log-rank test was carried out to compare survival between the two periods.

Health-related quality of life data were presented with means and SDs. Deviations in HRQOL from age- and gender-adjusted norm data were analysed with one sample *t*-tests (138). Differences in HRQOL between subgroups within the SCI population were analysed with independent sample *t*-tests. In addition we calculated effect sizes (139). The levels of ES were interpreted as small (i.e. 0.20), medium (i.e. 0.50), or large (i.e. 0.80) (140).

Multiple logistic regression (forward selection procedure) was used to identify predictors for obtaining work post-injury (141). A Kaplan-Meier plot was used to illustrate the time that had elapsed from injury to discontinuation of employment in different age groups (age at injury) in persons who obtained post-injury work. Cox proportional hazards regression analyses were used to study factors influencing early withdrawal from work, i.e. time from injury to discontinuation of employment in persons who obtained post-injury work. Several multiple Cox regression models and Akaike's Information Criterion (AIC) values were considered to select the final model (142). Both non-parametric and parametric tests were carried out to analyse differences in levels of life satisfaction (all 11 items) between currently employed and unemployed persons.

3.6. Review of employment literature

A review of the literature on RTW and other employment issues in SCI samples in different countries was carried out. The aim of this study was to present recent (2000-2006) results on RTW outcomes and employment in persons with SCI. The search strategies were as follows: The keywords 'spinal cord injuries', 'spinal cord disorder', 'spinal cord lesion', or 'spinal

cord disease' were each cross-indexed with 'employment', 'return to work', 'occupation', or 'vocational'. We limited our selection of publications to full-length articles in English from the years 2000-2006. Since even the best databases are incomplete, searches were made in seven different databases: PubMed/Medline, AMED (Allied and Complementary Medicine), (ISI) Web of Science, EMBASE, CINAHL, PsycInfo, and Sociological abstracts. The search strategy resulted in 1,521 references which were checked for duplications and were also controlled/scanned to meet the above-mentioned criteria (topic, publication years, language, full-length articles). After this selection, approximately 270 articles were checked more thoroughly for possible suitability for inclusion in the review. A total of 110 references met the inclusion criteria. Another two references were found elsewhere. In addition, a few references were collected for background information. Most of the papers were of US origin; very few references derived from less industrialized countries.

3.7. Ethical aspects

The study protocol was approved by the Regional Committee for Medical and Health Research Ethics, Oslo, Norway. Additionally, supporting documents were submitted twice: 1) concerning minor changes to the protocol; 2) concerning a possible study on non-respondents.

The fundamental principles of medical ethics were taken into account when planning the study, including respect for the patient's autonomy, a minimum of burden to the patient, and balancing of the risks, costs and benefits of medical action (143). All persons were asked for written informed consent, and their possibility of withdrawal from participation at any time during the study was underlined. Study participation did not imply any harm to the participant except for possible psychological strain in answering the questionnaires. Since the study included deceased persons, permission to extract data from their medical records and from the Cause of Death Registry

was necessary. In such cases an exception from professional secrecy was granted at the Department of Health and Social Affairs (from April 2008: the Norwegian Directorate of Health). The Data Inspectorate accepted the methods used for conducting the study including storing the data.

Non-respondents

Respondents are spokesmen for the target population. The response rate is important in judging the representativeness of the study sample. Since it has been indicated that persons with more severe conditions may be less likely to participate in population surveys, an application to undertake a so-called 'non-respondent study' on 58 persons with traumatic SCI was sent to the Department of Health and Social Affairs and to the Regional Committee for Medical and Health Research Ethics. The Department of Health and Social Affairs demanded an agreement by each non-respondent to the use of *any* data from their medical records. The existing Norwegian regulations, intended to protect the privacy of the individual, demand consent of each individual, both respondents and non-respondents, to use of any data from their medical records. The Regional Committee for Medical and Health Research Ethics in Oslo had, on the other hand, no objections to a collection of selected demographic and injury-related data from medical records, even without an agreement from the persons in question.

Studies of non-respondents are debatable in the light of ethical aspects (143). However, it has been argued that at a minimum, differences in age and gender between non-respondents and respondents should be given (144).

4. RESULTS (SUMMARY OF MAIN FINDINGS)

After the exclusion process (Fig. 2, page 36), 321 men and 66 women were included in the study (Table II). According to available knowledge, the included sample represents roughly 25-40 % of all persons who sustained a traumatic SCI in 1961-1982 in Norway (14;18).

Table II. Characteristics of persons with traumatic spinal cord injury (SCI) included in studies I-III

Characteristics	Study I Total population (n = 387)	Study I Deceased (n = 142)	Study II-III Participants (n = 165)
Men/women (n)	321/66	121/21	135/30
Age at injury (median years) (range)	27.9 (3-82)	52.3 (15-82)	21.4 (3-55)
Cause of injury (%)			
Sports	11	4	16
Assaults	4	2	5
Transport	46	37	53
Fall	32	49	19
Others	7	8	7
Unknown	1	1	1
Accident at work (%)	19	22	17
Level of injury (%)			
Tetraplegia	47	63	36
Paraplegia	53	37	64
Frankel classification (%)			
A	47	38	52
B	6	4	7
C	13	13	13
D	32	43	25
E	2	2	2
Complication(s) during initial rehabilitation (%)	58	55	56
Associated injury(ies) (%)	52	55	53
^a Occurrence of medical condition(s) and/or trauma(s) prior to SCI (%)	20	31	9
History of pre-injury alcohol or substance abuse (%)	6	10	2
Time period of injury 1961-1975/1976-1982 (%)	51/49	54/46	49/51

^aChronic conditions or severe traumas noted in each patient's medical record were included.

During the observation period up to 31 December 2002, 142 persons (37 %) died, and these deceased persons formed the basis of the study on mortality and causes of death (study I). Another eight persons emigrated from Norway. For the study on long-term survivors (studies II and III), the 237 persons who were still alive were asked to participate. A total of 179 persons (76 %) agreed to do so. However, for different reasons another 14 persons were unable to join the study.

4.1. ‘Mortality after spinal cord injury in Norway’ - (paper I)

This cross-sectional study of mortality in the 387 patients who sustained traumatic SCI in 1961-1982 showed that 121 men and 21 women (37 %) died during the observation period. The standard mortality rates were 1.8 in men and 4.9 in women, 2.4 in tetraplegic men and 7.6 in tetraplegic women, 1.3 in paraplegic men and 3.3 in paraplegic women. Risk indicators for death were as follows: higher age at injury, tetraplegia versus paraplegia, functionally complete SCI (Frankel scores A-C) versus functionally incomplete lesions (Frankel scores D-E), pre-injury cardiovascular disease, pre-injury psychiatric diagnosis, and pre-injury alcohol or substance abuse.

The most frequent causes of death were pneumonia/influenza (16 %), ischaemic heart diseases (13 %), and urogenital diseases (13 %). In the study population cause-specific SMRs were most markedly elevated for urogenital diseases, but were also increased for suicide, pneumonia/influenza, urogenital cancer (in men), and diseases of the digestive system (in men).

4.2. ‘Health-related quality of life in persons with long-standing spinal cord injury’ – (paper II)

Study II is a cross-sectional study in which health-related quality of life was assessed in persons with long-standing SCI. One hundred and sixty-two (132 men and 30 women) out of 165 persons who had sustained their injury more than 20 years previously completed the SF-36 questionnaire. The SF-36

results were compared with Norwegian norm data ($n = 5,152$) adjusted for age and gender. The persons with SCI showed decreased HRQOL concerning all domains as compared with the normal population, and the differences were significant regarding the subscales Physical Functioning, Bodily Pain, General Health, and Vitality, with effect sizes from medium to large. Relatively small differences in HRQOL were found between subgroups (within the SCI sample) based on gender, age, length of time since injury, marital status, region of residence, paraplegia versus tetraplegia, and AIS A-C versus D-E. Employed persons reported higher HRQOL than unemployed persons in four subscales (PF, RP, BP, SF), with medium to small effect sizes. HRQOL was lower in persons reporting health problems (79 %) than in those reporting no health problems at all, with medium to large effect sizes in six domains (RP, BP, GH, VT, SF, and MH). ‘Main health problems’ were merged into five groups according to those most frequently reported, namely pain, urogenital problems, ‘my disability’, musculoskeletal problems, and others. In addition the group ‘no health concerns’ was established. Pain was the most common ‘main health problem’ in the studied sample, and persons rating pain as their ‘main health problem’ reported significantly impaired HRQOL in five domains (RP, BP, VT, SF, RE) as compared to those who did not report pain as their ‘main health problem’.

4.3. ‘Employment of persons with spinal cord lesions injured more than 20 years ago’ - (paper III)

A total of 165 (135 men and 30 women) out of 237 persons with SCI of more than 20 years’ duration, participated in a study with focus on post-injury employment. The design was cross-sectional with use of retrospective data.

Sixty-five per cent ($n = 107$) of the participants obtained gainfully employment at some point in time after the injury. The odds (odds ratio) of obtaining work were higher in persons of younger age at injury, in

men than in women, in persons with paraplegia than in those with tetraplegia, and in persons classified as Frankel D-E compared with those with a more severe SCI. Only 58 (35 %) of the participants still had work at the time of the survey (2003-2004); 31 (53 %) full-time, 25 (43 %) part-time, two (3 %) unknown. Three persons retired with a pension on the basis of age. Persons who obtained post-injury work but subsequently stopped working prematurely ($n = 46$) had a mean age of 43 years at the time of withdrawal. Factors associated with a shorter time between injury and discontinuation of employment were higher age at injury, occurrence of injury after 1975 versus before, and a history of pre-injury medical condition(s). Life satisfaction was significantly better in currently employed participants as judged by the domains 'life as a whole', 'vocational situation', and 'financial situation'.

4.4. 'Return to work following spinal cord injury: a review' - (paper IV)

The studies included in the review confirmed mostly low employment rates after SCI in the respective countries. Among persons who were working at the time of the SCI, it was reported that 21-67 % returned to paid work after the injury, but few seemed to return to their pre-injury job. In studies including both persons who were employed and persons who were not employed at the time of the injury, it was found that the proportions with gainfully employment ranged from 11.5 % to 74 %. The interval between the injury and the RTW can be relatively long, and the employment rates improve with years after injury. It was concluded from the review that return to work is more likely in persons injured at a younger age. Those who sustain SCI during childhood or adolescence seem to have higher adult employment rates than do persons with adult-onset SCI. Further, the less severe the injuries or the higher the functional independence, the higher the employment rates. Persons with SCI who are not working report lower overall satisfaction and lower satisfaction with job opportunities and income compared with

employed persons. However, it was documented that many unemployed persons thought they were capable of working. Employment is associated with a higher level of activity, fewer depressive symptoms, fewer medical treatments and better overall adjustment.

Factors found to influence employment, barriers to work, and reasons for unemployment in persons with SCI were problems with transportation, health and physical limitations, lack of work experience, lack of education or training, physical or architectural barriers, perceived discrimination by employers, and loss of acquired benefits. Persons with SCI discontinue working at a younger age. Different interventions to help people obtain and/or maintain employment after injury have been developed, such as special RTW programmes, and tailored 'Supported Employment'. Unemployment in persons with SCI leads to significant costs, and improvement of the RTW rates would imply a significant reduction in expenditure for disability benefits and insurance funds.

Employment statistics are lacking for persons with SCI in less wealthy countries, and the high general unemployment rates, poverty and cultural differences make their situation very difficult.

5. GENERAL DISCUSSION

The discussion section of this thesis will focus on the following issues:

- First, aspects of the methods used in studies I-III will be considered, including the design, the material, the outcome measures, including questionnaires, and the statistical procedures. Possible sources of bias, as well as strengths, will be elucidated.
- Second, there will be a discussion on the methods used in the review (study IV).
- Third, the main results from all studies will be discussed.

5.1. Methodological considerations

Study design

We chose to make an observational study of survival and mortality after SCI as well as of selected outcomes of persons living with SCI for more than 20 years. In view of the above-mentioned study intentions (pages 33 and 34), the choice of a cross-sectional design with inclusion of retrospective data seemed to be the most suitable way of obtaining the information needed for this survey. With this design, it was possible to gather a relatively large amount of information with moderate resources (118). The access to retrospective data from medical records made it possible to investigate associations between possible risk indicators and outcomes such as mortality and employment. However, the choices of potential predictors were then restricted to those listed in the medical records (predominantly of a socio-demographic and injury-related nature). It is also important to be aware of the possible inaccuracy of retrospective data as a source of bias (118). It is unlikely that all data noted in the medical records are complete and correct.

A weakness worth mentioning is the possible lack of stability of outcomes in cross-sectional studies compared with longitudinal studies (118). Since the

collection of data referred to a certain time (one occasion), dynamic processes and changes will be difficult to illustrate.

In paper II, the term 'follow-up' has been used. This investigation did not have a 'follow-up' design, but it may be discussed whether or not the study design has something in common with a so-called 'follow-up' study: the persons included were all injured at a certain point in time in their lives (giving rise to the initial medical records studied retrospectively) and 'followed-up' at another point in time more than 20 years later (cross-sectional data: dates of death, causes of death, questionnaires and interviews). In the strict sense of the term, a 'follow-up' study is of a prospective nature intended to follow-up individuals to see what happens. A prospectively designed study would have offered opportunities of securing the quality of all the collected data and of controlling all data recording, for example. On the other hand, such an investigation would probably have a very long duration and be very expensive (118).

An advantage of our study design is the use of both postal questionnaires and a subsequent individual interview and clinical examination. This meant that the possibility that questions were misunderstood or interpreted differently, was reduced. However, the reliability of the answers at a face-to-face interview depends on openness and honesty (145;146). The same applies to persons who need help to fill in the postal questionnaire.

The roles of order and mode of questionnaires have been discussed in the sense of a so-called 'order effect' (147;148). In this study, 'SCI specific questions' (i.e. prevalence data on associated conditions and secondary conditions, see epilogue on page 84) were first introduced during the face-to-face interview, followed by an open-ended question on 'main health problem(s)', and next the SF-36. It is possible, therefore, that the answers/results on 'main health problem(s)' and HRQOL were negatively influenced by detailed questions about SCI-related problems.

To study causal associations is a challenge and needs great care when interpreting results from cross-sectional data. It is difficult to draw clear inferences concerning causality (118). For example, in study II, it is impossible to conclude that being unemployed causes reduced HRQOL, since the fact might be that poor health leads to unemployment and also that poor health causes an HRQOL reduction. A similar problem for discussion is seen in study III regarding the level of life satisfaction as compared between persons employed and those who are not employed.

Observational studies are linked with a number of possible biases, such as selection bias and confounding, and those in question are discussed below (149). On the other hand, this cross-sectional study was strengthened by the addition of retrospective data, the comparisons with normative data, and by using statistical procedures such as multiple regression analyses (commented on on page 63).

The material; validity; possible biases

The selected sample and the sample size are of importance concerning the external validity of the study:

There is no central SCI register in Norway covering persons injured 1961-1982. For practical considerations, the study group was therefore restricted only to persons admitted to SunRH. We roughly estimated that the population enrolled constituted about 25 % of all persons who suffered SCI in 1961-1975 and 40 % of those injured in 1976-1982 in Norway (14;18). However, there is little information on the methods used for selection of patients for rehabilitation at SunRH in the 1960s and the early 1970s, and the question whether the studied population is representative of the total Norwegian spinal cord injured population is therefore debatable. We have reasons to believe that persons experiencing grave initial medical complications in addition to the SCI at that time, were to a large extent treated in local hospitals. Further, persons with few neurological deficits probably received rehabilitation at

local institutions or at physiotherapy outpatient clinics. Thus, the studied individuals injured during the early period bring selection effect to the study results. This effect would probably lead to: 1) an underestimation of SMRs, if more severe cases with a higher risk of mortality were to a lower degree admitted to SunRH prior to 1975. The calculated SMRs based on persons injured after 1975 were higher compared with the SMRs calculated for persons injured earlier, even though improvements in the management of traumatic SCI over time were likely. At the same time, however, there was a continuous increase in longevity in the general population, which of course also influences the calculations of SMRs. 2) False positive results, for example for employment and HRQOL, may possibly have been obtained concerning persons still alive, if persons injured during the early period had better basic conditions than the SCI population at large.

The results may also be biased by the inclusion of 24 persons who were admitted to SunRH more than one year following injury. It seemed more advantageous, however, to include these persons than not to do so.

From a methodological point of view, the study was strengthened by the inclusion of persons who had survived at least one year post-injury, to avoid considerations of transient short-term effects on survival and the effects of the high mortality rates seen during the first months. Further, it seems to be advantageous that all participants (studies II and III) were at least 20 years post-injury; i.e. strengthening the generalizability to persons with traumatic SCI of long duration.

Volunteer bias may have influenced the results of studies II and III (118). The response rate of 76 % is relatively satisfactory, however. But, people who do not respond are a potential source of bias to estimates such as HRQOL, employment rates, life satisfaction, perceived health problems, and so on. Persons with more severe conditions may be less likely to participate in surveys. Thus, it is possible that those with a more severe impairment and/or

living a long distance from the hospital might not consider study participation feasible. Another aspect, which has been discussed to only a lesser degree in studies on SCI is the fact that persons occupied with work and social activities may be too busy to participate. This ‘theory’ is based on assertions given by some of the non-respondents in the current study. The comparisons between 35 (60 %) of the non-respondents and the study participants are shown in papers II and III (demographic, employment and injury-related data).

The conceptual understanding of the definition of the term ‘employed’ (‘employment’) needs to be discussed. We defined ‘employed’ as having paid work. A clear definition is important, especially when comparing the results with those of others, as some authors, for example, include students and/or homemakers in the ‘employed’ group, while others do not (see paper IV and also Table IV at pages 76 and 77). Further, it is important to be aware of the composition of defined subgroups within the study sample when interpreting the results: In study III, a relatively large proportion of those categorised as ‘not employed’ at the time of the injury were students aged 17-22 years. When looking at our unpublished data, it is clear that a substantial proportion of those who were students at the time of the injury obtained post-injury work at some point in time. It is likely that being a student at the time of injury offers better opportunities regarding the future working career, and indeed the young age also influences the situation favourably. Since the present study was carried out more than 20 years after the injury, the students had had enough time to begin work. The variable ‘employment status’ did not predict post-injury employment as seen in other studies (150), and the above-mentioned aspects may explain why.

In conclusion, the above-mentioned discussion indicates that the external validity of this investigation, and thus the generalizability of the results, to some degree might be affected. However, the study population was relatively large and there was almost a complete identification of all the persons in

question with the benefit of the national Central Population Register. Thus, we assume to have covered the majority of persons with traumatic SCI admitted to SunRH in 1961-1982. Another advantage is the fact that the National Health Service (National Insurance Scheme) allows all citizens to receive the necessary health care (subsidised) and the Patients' Rights Act gives everyone equal access to health care. Thus, this Norwegian study on spinal cord injured persons probably reflects the national SCI population better (as in other comparable Scandinavian studies) than in many other countries.

Outcome measures

Aspects of the use of data from the Cause of Death Register (study I), as well as of the use of specific instruments in studies II-III will be discussed below.

Data from the Cause of Death Register

Causes of death in *all* persons in question were obtained from the Cause of Death Register, and also a complete set of their death certificates. This is an advantage to study I. Nevertheless, the most difficult part of the current investigation was the study and reporting of causes of death, which gave rise to questions on the quality of data based on this register information. Our data, collected from the Cause of Death Register (i.e. the underlying cause of death), included a number of deaths caused by 'Unintentional injuries'. This surprising finding necessitated further investigation. From the death certificates it was clear that most of these 'Unintentional injuries' represented the injury which caused the SCI many years before death. Our recoding of causes of death listed as 'Unintentional injuries' as described on pages 37 and 38, brings bias to the cause-specific SMR results since the actual number of these deaths was reduced, but the expected number was not altered (see the discussion in paper I). In a Danish study on mortality in SCI, the SMRs for 'accidents' were low, as also seen in other studies on mortality after SCI (20).

DeVivo et al studied persons who sustained SCI in 1973-1984, and they found that 43 out of 854 deaths (SMR: 1.1) were caused by ‘Unintentional injuries’, and it seemed as if these injuries were subsequent to the SCI (59).

The SF-36

Different HRQOL instruments have been evaluated concerning their applicability in SCI populations, including the SF-36, and the importance of standardised instruments has also been emphasised (64;73;126).

The choice of a generic instrument allows comparisons with the general population. The SF-36 has previously been shown to be valid and reliable (128;129), and it is suitable for comparisons across countries (151). Further, this questionnaire has been translated into Norwegian, and the Norwegian version has shown good evidence of construct validity (130). Since then, several reports on HRQOL assessed with the SF-36 in different samples have been published in Norway. Norm data based on relatively large samples are available, as from the Norwegian Survey Archive, Norwegian Social Data Services (117). The SF-36 has also been used in a number of studies on persons with SCI (see Table III, page 72).

We decided not to use the summary scores PCS and MCS, because in samples with particularly low Physical Functioning scores, the MCS score will be highly inflated (see the discussion part in paper II) (71;72;125).

One concern about the appropriateness of the SF-36 in studies on SCI populations and other severely disabled populations is the inclusion of questions that refer to walking or climbing stairs (significant ‘floor’ effects, i.e. lowest possible score, with the PF domain), and the fact that the use of mobility aids remains unaddressed (68;72;74). In recent years, SCI-specific HRQOL questionnaires have been developed (152-154). However, there is still relatively little information on these instruments. This thesis does not add further to this information or to the discussion of these instruments.

The Life Satisfaction Scale-11

The LiSat-11 has been assessed concerning reliability and validity, and the results are satisfactory (107;133;155). This instrument has been used in previous research on people with disabilities, including persons with SCI, and it has been suggested that it may become one of the standard instruments on assessments for life satisfaction in SCI (136;156). The LiSat-11 has been used in Norwegian studies, for example in persons who have sustained multiple trauma and in persons with cerebral palsy (145;157). To my knowledge, there are no Norwegian norm data for LiSat-11, but for some comparisons we used results from a Swedish study that included normal population data (133).

Questionnaire on employment

The questionnaire on employment has some weaknesses. First of all, it is not a standard instrument tested for validity or reliability. Further, there is no documentation on its applicability. However, to assess the reproducibility of the questionnaire, it was answered twice by fourteen (9 %) respondents after a random selection. The results suggested that the reproducibility was good: 83 % of the answers on the second occasion were in accordance with the initial answers.

Perceived health problems

Perceived health problems were recorded in a non-standard way by using an open-ended question.

In the Norwegian language, the term 'health' is associated to a fairly large extent with the physical aspect (130), and it is therefore possible that mental health problems may have been under-reported by the participants.

It is also worth mentioning that 'health' is defined differently by different individuals (63). Many persons with SCI distinguish between their disability and their 'health' and do not define the disability itself to be a health problem, whereas other do (63;66;68). As an example, ten percent ($n = 16$) of the participants reported 'my disability' to be their main health problem, and

other participants stated that they did not regard their disability as a ‘health problem’.

Statistical considerations

The studies I and III were strengthened by the use of multiple regression analyses: The Cox proportional hazards regression model is broadly applicable and the most widely used method of survival analysis (118). Cox proportional hazards regression analyses were also performed to evaluate factors influencing the number of years that had elapsed from injury to discontinuation of employment. In study III, a multiple logistic regression analysis was carried out to determine possible predictors of post-injury employment. By using the statistical procedures described above, the influence of confounders was minimised.

It is common for *survival curves* to flatten out as events become less frequent, and an over-interpretation of the right-hand part of the curves should be avoided (studies I and III) (118). The Kaplan-Meier plot on survival of our SCI population in comparison with the general Norwegian population is probably of minor value. With the benefit of hindsight it is clear that we inexpediently compared a norm curve based on deaths in 2002 with a curve representing SCI deaths occurring during a 40-year period.

In study I, we recoded causes of death concerning ‘Unintentional injuries’ in the studied SCI population (as described on pages 37, 38, and 60), and therefore the SMRs on ‘Unintentional injuries’ are biased (see paper I). Further, some of the SMRs in the present study were computed on the basis of small numbers of deaths, resulting in uncertain values. When only few people are exposed to the explanatory variable, or when only few individuals have a characteristic or condition, the estimates may be imprecise and accompanied by a wide confidence interval. The reader should be aware of the existence of such tendencies in subgroups within the studied sample throughout the studies I-III.

Several comparisons were made by means of *t*-tests (or Mann-Whitney test) for continuous data, and the Chi squared test (or Fisher's exact test) for categorical outcome variables. Corrections for multiple testing were not found necessary, as the analyses were of a more exploratory nature (144).

Effect size (study II) is considered to represent the clinical significance of a relationship, and strengthened the interpretation of the HRQOL results. A highly significant relationship may be uninteresting if its ES is small.

Methodological considerations of the review study (study IV)

It may be debated whether the review paper included in this thesis is 'systematic' or not. According to the Cochrane handbook, a systematic review is characterised as follows: 'A systematic review attempts to collate all empirical evidence that fits pre-specified eligibility criteria in order to answer a specific research question. It uses explicit, systematic methods that are selected with a view to minimizing bias, thus providing more reliable findings from which conclusions can be drawn and decisions made' (113).

We sought to cover a broad part of the literature on RTW in persons with spinal cord injury. We endeavoured to present the different operational definitions of employment used, and to clarify the aims and main topic of each of the studies included, and their selected material (SCI population characteristics, duration of SCI, etc.) to make it possible for the reader to obtain as exact information as possible. A weakness of this review is the lack of an evident presentation of the evaluation of methods used for each publication included, as well as assessments on their validity. Further, the current review probably covers too many issues within the topic 'RTW'/ 'employment' to meet the criteria for a systematic review (115). Thus, the approach to summing up the literature on 'RTW in persons with SCI' has much in common with a narrative review (115). However, the sources used were comprehensive and the search strategy was explicit. In our review paper, results from the studies included are presented both as quantitative summaries

with use of tables and, for some of the issues, in a more descriptive form.

Did the review paper cover all relevant employment information in the SCI field? Databases are incomplete, but by making searches in seven different databases we attempted to capture the greater part of the available employment literature in the SCI field. Nevertheless, it seems as if a few studies were not embraced. Probably the key words 'participation', 'work', and 'integration/reintegration' would have added some references.

5.2. General discussion of main results

The most important achievement in this study is the identification of possibly preventable risk indicators for death such as certain medical conditions and risk behaviours, and also of common causes of death, in persons with chronic SCI. Through these results, it is possible to identify persons who run a higher risk of early mortality. We showed that the ratios of observed to expected deaths, the SMRs, were elevated in the studied SCI sample when this sample was compared with the general population, indicating that life expectancy is reduced in Norwegian persons with traumatic SCI. This information needs to be emphasised in order to maintain, or to put even more focus on preventive treatment to allow persons with SCI to achieve better longevity.

In persons who were still alive more than 20 years after SCI in this Norwegian study, the outcomes found for HRQOL were mostly more positive than those reported from other studies, but were still lowered compared to norms; they were worse in persons who were not employed, and in those who reported health problems such as pain and urinary tract problems. A significant result of the current study was the associations of possibly preventable factors with early withdrawal from work. Both the statements by study participants on their working life, and the review of documentation on the employment situation in persons with SCI, revealed low employment rates after the injury and a multitude of challenges related to return to work.

Survival

Information on survival and long-term consequences after SCI in Norway is required for a multitude of purposes, including assessment of service planning and of life planning by the injured person. During the acute phase after the injury and the initial rehabilitation, patients and their relatives often have an excessively pessimistic view regarding life expectancy after SCI. It is important to give the patients accurate evidence-based information on this topic. Many researchers have focused on the short- to medium-term mortality

(i.e. from the time of injury to 10 years post-injury) (6). The term 'long-term survival' is generally used to describe persons who have survived at least one or two year(s) after the injury (52;158).

Approximately 90 % of the studied Norwegian population survived the first 10 years with SCI, and 63 % were still alive more than 20 years after the injury. The proportion of deaths (37 %) was higher than was found in a comparable Danish study (27 %) (20). The highest SMRs were found for persons with tetraplegia, however we did not calculate SMRs according to the extent of the SCI, which would have been preferable. The mortality (SMR) was higher in women than in men, but it is important to note that the women constitute a smaller group and the result should therefore be interpreted with caution, as for all other small subgroups throughout this investigation. It should also be mentioned that the normal expectations of longevity are somewhat higher in Norwegian women than in men, and premature cases of death therefore influence the SMRs differently depending on gender. Other reasons for this gender difference were not found, including the SCI severity (level and extent of the SCI), injury aetiology, pre-injury medical conditions, or associated injuries additional to the SCI itself. In a recent Norwegian study by Hagen et al (20.8 % mortality within one year post-injury included), the same tendency towards an SMR difference between genders was found (19). From other studies it is reported that men are more likely to die early than women with SCI (2;49;53). On the other hand, comparison of SMRs across different countries is not an option, as the calculations are based upon expected death rates from the respective countries.

As mentioned in the introduction (page 23), the existing literature has documented a decline in the first-year mortality rates after SCI, but since the 1980s it seems that there has been little or no improvement either in annual mortality rates or in life expectancies after the second post-injury year (44;52;56;59). At the same time, Strauss et al refer to the improvement in life expectancies in the general population, and assert that the gap in life expectancies between persons with long-standing SCI and the general

population has not narrowed (52). Our comparison between persons injured in 1961-1975 and in 1976-1982 did not show any improvement in survival either, and furthermore the SMR calculated for the later period was higher. The improved longevity in the general Norwegian population must be taken into consideration. These findings also bring up the question of possible selection bias, and an overestimation of survival, as discussed on page 58.

Causes of death

The distribution of causes of death found in the current investigation, are in accordance with those reported by many authors (2;20;159), and some of the actual cause-specific SMRs are supported by the recent findings by Hagen et al (19). We did not investigate changes of trends in causes of death or in cause-specific SMRs between time periods.

The prevalence rates of causes of death provide indirect evidence of the importance of prevention and control of various diseases:

Pneumonia/influenza was the leading underlying cause of death in the studied sample, in accordance with several other reports (2;20;49;59;61). Although pulmonary deaths are common in the general population (160), the calculated SMRs in the SCI sample were markedly elevated and confirmed that deaths from pneumonia/ influenza are approximately six to nine times higher in persons with such injury. This result is a significant reminder of the importance of all preventive measures concerning lung function in persons with spinal cord injury, including efforts to maintain or improve the vital capacity, better cough strength and assistance, prevent smoking and probably to consider pneumococcal vaccination and flu vaccination as recommended (161).

Cardiovascular abnormalities have been well documented in persons with spinal cord lesions (162-164). The risk of developing a cardiac complication both in combination with high blood pressure (as in paraplegic persons) and without high blood pressure (as in tetraplegic persons) increases per year with

age in individuals with SCI (78). There have been indications of higher prevalence rates of CVD risk factors such as obesity, lipid disorders, metabolic syndrome, insulin resistance and diabetes in persons with SCI (165). Ischaemic heart disease was the second most common underlying cause of death in our sample, which also reflects the situation seen in other studies (2;20;45;49;59;61). On the other hand, the SMRs did not exceed 1.0, and hence deaths caused by ischaemic heart disease did not exceed those in the general Norwegian population. Nevertheless, the result indicates a challenging clinical issue, especially when considering that persons living with SCI are likely to grow into older age with an accompanying risk of an increase in CVD.

International SCI literature has proven a trend towards a decrease in deaths caused by diseases of the urogenital system (8;49;60;61). This study showed that diseases of the urogenital system represented the most elevated cause-specific SMRs in both women and men with spinal cord lesions. There is no previous report to indicate whether these results imply a tendency to improvement or not in the Norwegian SCI population. However, the high SMRs show that there is still room for improvement concerning deaths caused by diseases of the urogenital system in persons with SCI. Another important finding was the increased SMR for cancer in the urinary tract, which supports other reports on this topic (166;167). The above results indirectly suggest that a continuous focus on bladder management is of particular importance.

Although the median age of the studied persons who committed suicide was somewhat lower than that of the other persons who died, it is important to note that the age at suicide ranged from 22 to 83 years in this group. One of these persons was registered as having a psychiatric disorder before the injury. No information on illness, psychological aspects, or quality of life during the years between the initial rehabilitation and death was available for analyses on risk indicators of deaths. Several studies on normal populations document that psychiatric disease is related to suicide (168-170). The present

cause-specific SMR results on suicide are in agreement with the findings in another Norwegian study (19). Concerning these high cause-specific SMRs, it is also important to consider the reports on international studies investigating the topic of suicide with the aim of learning more about possible risk indicators. Hartkopp et al highlighted their documentation on suicide in persons with a marginal SCI (Frankel E), and indicated that insufficient physical and social support combined with increased expectations regarding recovery in these persons might influence their burden of coping (62). Other authors have also shown an increase in suicide rates among persons with SCI (5;61;171;172).

Factors associated with mortality

Krause et al underlined the importance of more knowledge from epidemiological research in the SCI field, documenting the risks and protective factors in relation to early mortality (173;174). Research that identifies health and secondary conditions associated with death provides information contributing to a better understanding of factors related to premature mortality after SCI. Our results point to three types of possibly preventable or treatable factors in relation to mortality, namely impaired health (cardiovascular disease), risk behaviour (substance abuse or alcohol abuse), and psychological dysfunction (psychiatric disorders). A recent report on health and risk of mortality, emphasises the importance of interventions to allow early identification of, for example, depressive disorder (173). The authors identified the following health risk factors for mortality after SCI: pressure ulcers, urinary tract infections, amputations or fractures, and the development of a depressive disorder.

Another study by Krause & Carter addressed the risk of early mortality and its relationship to environmental factors, and it was concluded that low income and poor social support are predictors of mortality after SCI (174). These findings indirectly elucidate another factor, namely the importance of

more support in obtaining and keeping employment as discussed in papers III and IV.

Not surprisingly, higher age at injury, tetraplegia, and Frankel scores A-C emerged as significant risk indicators of death in our Cox proportional hazards regression analysis. Nevertheless, the proportion of persons classified as Frankel A-C was higher among the survivors, but Frankel class was highly correlated with age, which explains the results from the regression analysis.

Persons surviving more than 20 years with SCI

In comparison with deceased persons, those who survived more than 20 years with SCI were significantly younger and healthier at injury, more of them had a lower level of injury, and also a higher proportion sustained their SCI due to a transport accident. Unique contributions of this study to the existing literature are the results regarding outcomes on HRQOL in persons injured more than 20 years ago, their main health problems, and their employment situation.

Health-related quality of life in our participants was decreased to varying extent in all domains compared with Norwegian norms. This broad impact across SF-36 domains highlights the need for multidisciplinary treatment of both physical and psychological aspects of SCI, although the greatest burden appears to be on physical aspects of health (72;73). However, when the SF-36 results from study II are compared with the findings by others (Table III, page 72), there is a clear indication that HRQOL is better in the Norwegian SCI sample than has been reported from other studies. The current results focus on persons injured more than 20 years ago, in contrast to many studies in which HRQOL is assessed in more heterogeneous SCI populations, when the length of time post-injury matters. Since the Norwegian sample only comprised persons injured more than 20 years previously, there is a possible effect of adaptation to their disability, and/or the effect of healthier persons analogous to survival effects (36;88;175).

Table III. Summary of studies on HROOL assessed with the SF-36 in persons with SCI

Authors; year; country	Participants, n (response %)	Age (yrs), mean (SD)	Time since injury (yrs)	SF-36							
				PF	RP	BP	GH	VT	SF	RE	MH
Lidal et al, 2008, Norway, (study II)	162 (70 %). Traumatic SCI	50 (10.1)	>20 (mean 27)	36.3*	74.1	64.2*	69.4*	59.3*	83.0*	85.0	80.2
Tate et al, 1997, USA (176)	n<30 ♀. Traumatic SCI	47	Mean 7.4 yrs	29.6	39.1	56.4	55.2	51.5	82.5	90.0	70.8
Westgren & Levi, 1998, Sweden (36)	320 (91%)	42 (range: 17-78)	≤4 yrs n=78 ≥4 yrs n= 242	42.5*	57.2*	57.2*	63.9*	61.4*	76.7*	70.4*	74.8*
Andresen et al, 1999, USA (73)	183 (78.2%), SCI veterans	50.5 (12.7) (range: 21-81)	Mean: 18.9 (SD: 11.4)	21.2	41.5	49.4	55.2	52.9	66.9	81.5	73.6
Tate et al, 2002, USA (177)	99	36 (13)	Mean: 6 (SD: 3)	32.6	50.8	53.1	70.8	90.9	76.1	52.4	61.5
Leduc & Lepage, 2002, Canada (71)	586 (63%)	<30=10%, 30-40=25%, 41-50=29%, 51-60=25%, >60=11%	<10=37% 10-20=29% >20=34%	23.9*	38.3*	39.0*	42.2*	45.7*	38.7*	45.7*	44.3*
Forchheimer et al, 2004, USA (125)	215. Traumatic SCI	38.8 (14.5)	1-13	26.6*	40.7*	42.2*	44.4*	46.8*	43.0*	49.0*	48.3*
Lucke et al, 2004, USA (178)	10. Traumatic SCI	Mean: 32	6 months	19.3	46.4	59.0	64.9	55.7	73.2	42.9	75.4
**Kreuter et al, 2005, Australia and Sweden (40)	Austr: 89 (52%) Swed: 71 (66%)	42 37	5 7	28 20	60 35	52 52	56 56	56 52	70 62	75 60	72 72
† Haran et al, 2005, Australia (72)	305 (56%)	45 ±14 (16-82)	Mean: 16±12 (1 month - 61 yrs)	18 †18*	66 †64*	68 †66*	63 †61*	61 †59*	75 †74*	82 †77	76 †75
Elfsröm et al, 2005, Sweden (39)	256 (71%). Traumatic SCI	43.9 (15.9)	Mean: 8.9 (7.0) Range 1-40	33.0*	58.9*	50.9*	59.6*	52.9*	67.1*	73.1*	68.9*
Oh et al, 2005, Korea (179)				20.9*	26.7*	31.4*	42.9*	53.6*	51.4*	62.0*	45.6*
Celik et al, 2007, Turkey (180)	30	39 ±14. Range (16-32)	45 months ±80 (Range: 3.5-384)	18.2*	20.0*	46.9*	45.9*	42.0*	42.0*	47.8*	57.6*
Krahn et al, 2009, USA (80)	270. Traumatic SCI	44.8 (13.8)	16.8 (12.3)	17.5*	35.4*	-	-	50.8*	-	-	67.4*

* Significant difference from norm scores from the country in question (Leduc & Lepage used American norms). ** The given SF-36 scores are based on interpretation of a diagram from the original article by Kreuter et al, and the scores given in this Table are therefore imprecise. † The results are standardised (age). Austr = Australia; Swed= Sweden.

However, there are no comparable data on HRQOL in Norwegian persons with SCI of shorter duration to document improvements over time. Another possible explanation for the fairly good SF-36 results is the fact that Norway has one of the best standards of living in the world. When interpreting the results, it is also important to be aware of the possible selection bias, although this issue is probably applicable to other studies in the Table as well.

Questions on limitations to physical functioning (RP) and limitations to emotional functioning (RE) address the situation in the last four weeks. Persons living with a disability for more than 20 years possibly perceive a higher grade of medical, physical and psychological stability, resulting in relatively high scores in these two domains.

In 1995, Anke et al investigated pain and quality of life in a Norwegian sample with traumatic SCI within two years after injury, and concluded that pain causes emotional distress in addition to distress associated with that of the spinal cord injury itself (181). Recently, self-rated health and its relationship to secondary conditions in SCI were studied, and chronic pain was reported to be the most frequent significant problem, as also noted in other studies (80). The current study shows that a substantial proportion of individuals with SCI still have a high prevalence of health concerns many years after the injury, whereof pain and next urinary tract problems are the most frequently reported problems. Participants who assessed pain as their main health problem reported significantly decreased scores with six domains of the SF-36 compared with the others (study II), and significantly more unemployed persons reported pain as their main health concern (study III). We did not explore details on the type of SCI pain, or of its intensity or duration, but this has been dealt with in an extensive amount of literature (as recently reviewed by Dijkers et al), so the current finding just highlights pain as a significant problem even several years post-injury (182).

The results showed a decrease in HRQOL (study II) and in life satisfaction (study III) in the 65% currently unemployed participants compared with those still at work, confirming previous reports on employment status and quality of

life in persons with SCI, showing that persons still at work are more satisfied than those who are not (36;94;95;105;134). However, it is important to mention that we did not gather information on their reasons for unemployment or withdrawal from work. It is possible that those who did not return to work after SCI or withdrew early from work, experienced more health problems, such as pain, and/or other barriers to employment; i.e. problems which in themselves might also affect the levels of HRQOL and life satisfaction. It is therefore difficult to draw a firm conclusion on causality. Study II clearly showed that persons who claimed to have no health problems reported markedly better HRQOL (with six subscales of the SF-36) compared to persons with perceived health problems.

The employment situation in the Norwegian SCI sample compared to international employment data for persons with SCI, including review results:

The results from study III were in accordance with our review results showing that the most successful RTW outcomes were seen in persons injured at a younger age, of male gender, and in those classified as having a less severe injury. A total of 65 % of the participants obtained work post-injury, but only 35 % were still employed at the time of the study. In Table IV (pages 76 and 77), the RTW rate in the Norwegian sample can be compared with rates from other recent studies (2006-2009), most of which were based on reports from persons with a shorter duration of SCI. The Table includes two qualitative reports. The studies listed in the Table also illustrate differences in the operational definitions of employment used and differences in study settings (103). Our results are based on reports of gainful employment at *some* time after injury and *at* the time of the survey, which means that there was a wide range of time in which the participants could have obtained work post-injury. As reported in paper IV, Krause & Coker showed in a longitudinal study in 2006, that the percentage number returning to work after SCI increased

during the first 15 years post-injury (183). We did not obtain information on employment at different times post-injury, or on the time that it took to regain work. On the other hand, our results indicate that many persons withdrew from work at relatively young age, and thus confirmed the finding in the literature review of a tendency for persons with SCI to discontinue working at a younger age than non-disabled persons. Pflaum et al concluded that persons with SCI are far more likely to work than has been suggested in other US studies, but also that persons with SCI do have significantly shortened working lives (184). The authors listed several factors associated with being employed in any given year, including the employment status at injury. Other studies have demonstrated that education as well as pre-injury employment are among factors with a positive influence on RTW (184-192). Lack of work experience or lack of sufficient education or training was reported to be among the barriers to work in the reviewed papers (study IV). In our investigation, neither pre-injury employment status nor pre-injury occupation proved to be predictors of post-injury work. Some aspects of this topic have been discussed on page 59, where it is pointed out that both the chosen definition of 'employment' and the interval between the SCI and the time of the study must be taken into account when interpreting the results.

Both medical and non-medical factors determine employment outcomes after SCI, as demonstrated in the review results on return to work after the injury (paper IV). In accordance with the existing literature, we found that age, gender, injury severity and neurological level were all predictors of obtaining work after injury. A surprising finding was the higher risk of early withdrawal from work in persons who sustained injury after 1975 compared to persons who sustained injury before 1975. However, the previous discussion on selection bias and also the fact that persons injured during the early period were younger at injury, might partly explain this result (in addition, see the discussion part of paper III).

To return to pre-injury medical conditions: We also found that pre-injury diseases were associated with early withdrawal from work in our sample.

Table IV. Summary of recent (2006-2009) studies with employment as the main topic in individuals with spinal cord injury (SCI)

Author(s); year ; country	Study: Participants, n (participation %)	Age (yrs), mean (SD); range	Severity of SCI	Mean time since injury, (SD)	(% employed at data collection); comments	Return to work (%)
Lidal et al, 2009, Norway, study III	165 (70%); traumatic SCI	23 (9.7) at injury and 50 (10.1) at data collection	36% tetra (28% Frankel A-C), 64% para (55% Frankel A-C)	27 (4.3) yrs Range 20-37	65 (35); All participants were >20 yrs post-injury. <i>Def:</i> Paid employment (homemakers and students were not classified as employed)	
Arango-Lasprilla et al, 2009, USA (190)	11,424	32.0 (12.3) at data collection	51.9% tetra, 48.1% para. 49.2% were compl	One year	15.4; employed Caucasians: 16.5%, employed Hispanics: 7.5%, i.e. a significant difference. <i>Def:</i> Employed vs. unemployed or other (i.e. homemakers, on the job training, sheltered workshop, retired, students and other were not classified as employed)	
Murphy et al, 2009, Australia (189)	72; traumatic SCI injured mid-2003 to march 2005	35.4 (15.0) in unemployed	58.3% tetra , 41.7% para. 57% AIS A	One year	27.5. <i>Def:</i> Some paid employment at follow-up vs. no paid employment.	
Kurtaran et al, 2009, Turkey (191)	129; traumatic SCI	36.1 (12) at data collection	18.8% tetra (6.8% compl), 81.3% para (54.7% compl)	43.4 (38) months	14.6. <i>Def:</i> Paid employment (i.e. students and homemakers were not classified as employed)	
Lin et al, 2009, Taiwan (192)	219 (51%); traumatic SCI	At injury: 35.7 (11.8) in those employed and 41.7 (15.4) in unemployed	20% AIS A, 14% AIS B, 16% AIS C, 50% AIS D	3.2 (1.3) yrs	32.9 (32.9); inclusion: employed pre-injury. <i>Def:</i> Working in the competitive labor market, self – employed, a homemaker, or a student	
van Velzen et al, 2009, the Netherlands (193)	118 (52%);	38.0 at data collection	15% tetra and 85% para. 64% compl	One year	33% were employed one year post-injury. Only persons employed at injury included. <i>Def:</i> Paid employed at least one hour /week	
Fadyl et al, 2009, New Zealand (194)	13 (seven male, six female)	Median 44 (range 22-58) at injury	Participants were selected to represent a variation of injury severity / type of impairment	Median 8 months Range 2 months-10 yrs	<i>Qualitative study:</i> In depth interviews The findings illustrate the complexity of decisions about working after SCI.	
Krause et al, 2008, USA (92)	1296; traumatic SCI	27.2 at injury, 42.2 at data collection	52% tetra. 23% were 'ambulatory'	15.1 (at least one year)	(35.9). <i>Def:</i> Paid employment	

Rowell & Connell, 2008, Australia (195)	182 (72%) and of these n=146 tetra	26 yrs at injury, 43 at data collection	100% tetra	(29,7). <i>Def:</i> Employed vs. unemployed / looking for work/ not looking for work / or in training
Jongbloed et al, 2007, Canada (104)	357 (44%);	46 (14.7), 17-98 at data collection	26% compl tetra, 40% compl para. 30% incomplete	(31), 58% were unemployed. <i>Def:</i> Paid employment (?)
Isaksson et al, 2007, Sweden (196)	13 women, traumatic and non-traumatic SCI	Range 25-61 at data collection		<i>Qualitative study:</i> In depth interviews showed that the participants went through complex changes over time that influenced their participation in occupation.
Valtonen et al, 2006, Sweden (105)	182 (50%); traumatic SCI	30.5 at injury, 44.7, range 22-64 at data collection	47% tetra. 62% were non-functional ambulators	47. <i>Def:</i> Employment included full-time or part-time work and students.
Pflaum et al, 2006, USA (184)	20,143; traumatic SCI	37	52% tetra. 49% AIS A, 10% AIS B, 11% AIS C, 30% AIS D	Overall employment rate peaked at age 27 yrs at about 36% and fell steadily thereafter. <i>Def:</i> Employed in the competitive labor market vs. all others (except students and those who were retired pre-injury)
Krause & Terza, 2006, USA (187)	615 (81%); traumatic SCI	25.2, 1-80 yrs, at injury. 43.0, range 23-93 yrs at data collection	56% tetra	(43). <i>Def:</i> Gainfully employment

AIS: ASIA Impairment Scale, ASIA: American Spinal Injury Association (International Neurological Standards for Classification of Spinal Cord Injury)

tetra: tetraplegia; para: paraplegia; compl: complete SCI; incompl: incomplete SCI; SD: standard deviation; yrs: years

Def: Definition of the term 'employment' used in the study.

Early attention to patients with co-morbidities needs to be highlighted, not just regarding the risk of mortality, but also in relation to their decreased HRQOL as described above, and to their excess challenges related to maintained employment. Moreover it is of interest that a recent investigation has addressed income and employment in relation to mortality (174).

It has been shown that high disability benefits reduce the likelihood that the unemployed will secure work (184). The social welfare benefits and probably to some degree the level of unemployment in Norway, might have influenced the employment results in study III. The pattern of earlier withdrawals from work in participants injured in the later period is compatible with the incidence of disability pensions in national rates (see the elaborated discussion in paper III). Factors that might also have led to an increase in the number of people applying for a disability pension in recent years are possible changes in the rehabilitation programmes over time, with more focus on coping, and on daily occupations, as well as expectations of and attitudes towards persons with SCI.

In the Scandinavian countries, disability benefits, social rights, societal resources, and the labour markets are related to some degree (197). It is therefore more suitable to compare our results (Table IV) with other Scandinavian reports than, for example, with US results. As supplementary information, Statistics Norway recorded that among disabled people in Norway in 2008, 48 % were gainfully employed, and the difference from the norm was smallest in the youngest persons (198).

The review results (study III) illustrate that employment is an important outcome in studies on persons with spinal cord lesions, and a large number of articles include various information on RTW issues. There are still high unemployment rates today in persons with SCI in countries of all continents, and especially in less industrialised countries. Further, although there are several reports of barriers to returning to work after SCI, relatively little is known about what influences people's own decisions about their employment

following this injury (194). The main challenges in attempts to increase the RTW rates are probably related to the information, obtained from the literature review, on self-reported barriers to employment such as transportation, health and physical limitations, lack of work experience, lack of sufficient education or training, physical or architectural barriers, discrimination by employers, and loss of benefits. Information on barriers to work and reasons for early withdrawal from work was not collected in the Norwegian study sample. However, the following statement by the Norwegian Association of Disabled highlights this topic:

'Despite the fact that human rights and Norwegian law state that no one shall be discriminated regarding education or employment, the reality is different. Many disabled are excluded because of discriminatory attitudes, little flexibility and lack of facilitation' (199).

6. CONCLUSIONS AND IMPLICATIONS

This study is the first to confirm that life expectancy is reduced in Norwegian persons with chronic traumatic SCI, and it also enhances the insight into common causes and predictors of death. The findings affirm the importance of avoiding risk behaviours such as alcohol or substance abuse, as well as of paying more attention to medical conditions such as cardiovascular diseases and psychiatric diagnoses, in effort to increase longevity in persons with SCI. The results also indicate that common causes of death in Norwegians with traumatic SCI are mostly the same as are reported in the international SCI literature, namely pneumonia/influenza, ischaemic heart diseases, and urogenital diseases.

It has been documented in the present study that Norwegian persons living with SCI for several years have decreased HRQOL compared to norm data. This suggests room for improvements, and the findings point out better pain management as well as greater attention to problems related to urinary tract function as possible targets for intervention. The most frequent health concerns reported by the studied persons with long-standing SCI were, in addition to pain and problems from the urinary tract, ‘my disability’, and musculoskeletal problems. Unemployment seems to be another factor associated with reports of impaired HRQOL, and thus more emphasis on removing barriers to work is another target for intervention.

The study sheds light on some important aspects concerning employment after SCI, including risk indicators of unemployment after SCI, low employment rates, early retirement, and risk indicators of early withdrawal from work. Study participants who were still at work at the time of the study reported a higher level of life satisfaction than those who had withdrawn from work; although our findings do not indicate causality.

According to the review, the employment situation after SCI has received much interest by reasons of the psychological, social, financial, and political implications. Employment has been linked to medical adjustment. However,

the premises for obtaining and maintaining work in persons with disabilities, such as SCI, vary between countries. An overall finding is that the RTW rates are low in persons with spinal cord lesions. Many authors have documented factors that have the potential to influence RTW and employment in individuals with SCI.

In summary, this thesis enlightens some of the complexity involved concerning survival and other long-term consequences after SCI. Hopefully, the challenges described above will lead to improved health service and management programmes. The findings on risk indicators for death should serve as markers for increased risk of early mortality. Key issues in persons with spinal cord lesions include the role of prevention in promoting longevity, improving the prevention of medical complications and long-term consequences, and optimising treatment of perceived health problems, such as pain and urinary tract problems. The current results reflect the importance of structured long-term follow-up.

Future research

The present study has indicated the need for further investigations on a number of topics: Up-to-date knowledge on mortality after SCI is required for a multitude of purposes, including guidance of intervention strategies to promote greater longevity, life planning by the injured persons, and improved service planning. To explore recent trends in mortality and causes of deaths in persons with traumatic SCI, and expand the scope to include persons admitted for rehabilitation at all three national Spinal units in Norway, would be most valuable.

Further research is also needed concerning employment outcomes at different times after SCI, perceived barriers to work, motivations for work, and reasons for withdrawal from work. More information on health conditions, including medical co-morbidities, in relation to employment in SCI is needed in the

search for causal connections. Few longitudinal studies of employment have been conducted in persons with SCI, and such studies are recommended to achieve a more complete picture of the employment situation in samples of individuals with SCI. Different interventions to help people obtain and/or maintain employment after injury should be further developed.

Epilogue

Supplementary to the issues elucidated in this thesis, it is appropriate to inform the reader of the following: The participants ($n = 165$) also answered several questionnaires that have not yet been statistically analysed, and thus are not included in this thesis. These questionnaires are the Sense of Coherence Scale, Fatigue Questionnaire, Fatigue Severity Scale, The Hospital Anxiety and Depression Scale, our own constructed items on personal assistance and orthopaedic/technical aids, and prevalence data on medical complications and use of medication. A medical status inquiry including blood-sample analyses was carried out.

In hindsight, it seems clear that the above-mentioned data collection was very broad, and a more incisive plan for the study would have been favourable. Data on these topics were collected, but they are not included as a part of this thesis. However, the future plan is to analyse these data and to present the results.

In addition to the collected, quantitative data presented and discussed in this thesis, I want to underline that my personal meetings with each spinal cord injured individual, and the stories of their lives that they shared with me, made strong impressions on me. Despite lack of some information that could have been presented in addition to that given in this thesis, I hope that the participants are comfortable with the selected findings and the conclusions presented.

7. REFERENCES

- (1) The Norwegian Association of Disabled. Who are disabled - and what is disability? <http://www.nhf.no/2003>. (Norwegian)
- (2) Frankel HL, Coll JR, Charlifue SW, Whiteneck GG, Gardner BP, Jamous MA, et al. Long-term survival in spinal cord injury: a fifty year investigation. *Spinal Cord* 1998;36(4):266-74.
- (3) Freed MM, Bakst HJ, Barrie DL. Life expectancy, survival rates, and causes of death in civilian patients with spinal cord trauma. *Arch Phys Med Rehabil* 1966;47(7):457-63.
- (4) Geisler WO, Jousse AT, Wynne-Jones M. Survival in traumatic transverse myelitis. *Paraplegia* 1977;14(4):262-75.
- (5) Geisler WO, Jousse AT, Wynne-Jones M, Breithaupt D. Survival in traumatic spinal cord injury. *Paraplegia* 1983;21(6):364-73.
- (6) Samsa GP, Patrick CH, Feussner JR. Long-term survival of veterans with traumatic spinal cord injury. *Arch Neurol* 1993;50(9):909-14.
- (7) Sneddon DG, Bedbrook G. Survival following traumatic tetraplegia. *Paraplegia* 1982;20(4):201-7.
- (8) Whiteneck GG, Charlifue SW, Frankel HL, Fraser MH, Gardner BP, Gerhart KA, et al. Mortality, morbidity and psychosocial outcomes of persons spinal cord injured more than 20 years ago. *Paraplegia* 1992;30(9):617-30.
- (9) Munroe D. The rehabilitation of patients totally paralyzed below the waist, with special reference to making them ambulatory and capable of earning their own living* V. An end-result study of 445 cases. *New Engl J Med* 1954;250:4-14.
- (10) WHO. Preamble to the Constitution of the World Health Organization as adopted by the International Health Conference, New York, 19-22 June, 1946; signed on 22 July 1946 by the representatives of 61 States (Official Records of the World Health Organization, no. 2, p. 100) and entered into force on 7 April 1948. <http://www.who.int/about/definition/en/print.html> 2003
- (11) World Health Organization. International Classification of Functioning, Disability and Health. Geneva: 2001.
- (12) World Health Organization. Towards a common language for function, disability and health. <http://www.who.int/classification/icf> 2002
- (13) Trieschmann RB. Spinal cord injuries: psychological, social, and vocational adjustment. Second ed. New York: Demos Publications; 1988.

- (14) Gjone R, Nordlie L. Incidence of traumatic paraplegia and tetraplegia in Norway: a statistical survey of the years 1974 and 1975. *Paraplegia* 1979;16(1):88-93.
- (15) McAdam R, Natvig H. Stair climbing and ability to work for paraplegics with complete lesions - a sixteen-year follow-up. *Paraplegia* 1980;18(3):197-203.
- (16) Hagen EM, Aarli JA, Grønning M. Patients with traumatic spinal cord injuries at the department of neurology, Haukeland Hospital 1952-99. *Tidsskr Nor Lægeforen* 2001;121(28):3273-5. Norwegian.
- (17) Hagen EM, Aarli JA, Grønning M. The clinical significance of spinal cord injuries in patients older than 60 years of age. *Acta Neurol Scand* 2005;112(1):42-7.
- (18) Hagen EM, Eide GE, Rekand T, Gilhus NE, Grønning M. A 50-year follow-up of the incidence of traumatic spinal cord injuries in Western Norway. *Spinal Cord* 2009 Oct 13; [Epub ahead of print]:1-6.
- (19) Hagen EM, Lie SA, Rekand T, Gilhus NE, Grønning M. Mortality after traumatic spinal cord injury: 50 years of follow-up. *J Neurol Neurosurg Psychiatry* 2009 (Published online 2. September 2009)
- (20) Hartkopp A, Brønnum-Hansen H, Seidenschmur A-M, Biering-Sørensen F. Survival and cause of death after traumatic spinal cord injury. A long-term epidemiological survey from Denmark. *Spinal Cord* 1997;35(2):78-85.
- (21) Biering-Sørensen F, Pedersen V, Clausen S. Epidemiology of spinal cord lesions in Denmark. *Paraplegia* 1990;28(2):105-18.
- (22) Hansen RB, Biering-Sørensen F, Kristensen JK. Bladder emptying over a period of 10-45 years after a traumatic spinal cord injury. *Spinal Cord* 2004;42(11):631-7.
- (23) Hansen RB, Biering-Sørensen F, Kristensen JK. Urinary calculi following traumatic spinal cord injury. *Scand J Urol Nephrol* 2007;41(2):115-9.
- (24) Biering-Sørensen T, Hansen RB, Biering-Sørensen F. Home aids and personal assistance 10-45 years after spinal cord injury. *Spinal Cord* 2009;47(5):405-12.
- (25) Biering-Sørensen F, Hansen RB, Biering-Sørensen J. Mobility aids and transport possibilities 10-45 years after spinal cord injury. *Spinal Cord* 2004;42(12):699-706.
- (26) Finnerup NB, Faaborg P, Krogh K, Jensen TS. Abdominal pain in long-term spinal cord injury. *Spinal Cord* 2008;46(3):198-203.
- (27) Biering-Sørensen F. Management of spinal cord lesions. State of the art. 2002.

- (28) Ahoniemi E, Alaranta H, Hokkinen E-M, Valtonen K, Kautiainen H. Incidence of traumatic spinal cord injuries in Finland over a 30-year period. *Spinal Cord* 2008;46(12):781-4.
- (29) Dahlberg A, Alaranta H, Sintonen H. Health-related quality of life in persons with traumatic spinal cord lesion in Helsinki. *J Rehabil Med* 2005;37(5):312-6.
- (30) Dahlberg A, Kotila M, Leppänen P, Kautiainen H, Alaranta H. Prevalence of spinal cord injury in Helsinki. *Spinal Cord* 2005;43(1):47-50.
- (31) Kannisto M, Merikanto J, Alaranta H, Hokkanen H, Sintonen H. Comparison of health-related quality of life in three subgroups of spinal cord injury patients. *Spinal Cord* 1998;36(3):193-9.
- (32) Saikkonen J, Karppi P, Huusko TM, Dahlberg A, Mäkinen J, Uutela T. Life situation of spinal cord-injured persons in Central Finland. *Spinal Cord* 2004;42(8):459-65.
- (33) Levi R, Hultling C, Seiger Å. The Stockholm Spinal Cord Injury Study. 3. Health-related issues of the Swedish annual level-of-living survey in SCI subjects and controls. *Paraplegia* 1995;33(12):726-30.
- (34) Levi R, Hultling C, Nash MS, Seiger Å. The Stockholm Spinal Cord Injury Study: 1. Medical problems in a regional SCI population. *Paraplegia* 1995;33(6):308-15.
- (35) Divanoglou A, Levi R. Incidence of traumatic spinal cord injury in Thessaloniki, Greece and Stockholm, Sweden: a prospective population-based study. *Spinal Cord* 2009;47(11):796-801.
- (36) Westgren N, Levi R. Quality of life and traumatic spinal cord injury. *Arch Phys Med Rehabil* 1998;79(11):1433-9.
- (37) Levi R, Hultling C, Seiger Å. The Stockholm spinal cord injury study: 4. Psychosocial and financial issues of the Swedish annual level-of-living survey in SCI subjects and controls. *Paraplegia* 1996;34(3):152-7.
- (38) Levi R, Hultling C, Seiger Å. The Stockholm Spinal Cord Injury Study: 2 Associations between clinical patient characteristics and post-acute medical problems. *Paraplegia* 1995;33(10):585-94.
- (39) Elfström ML, Rydén A, Kreuter M, Taft C, Sullivan M. Relations between coping strategies and health-related quality of life in patients with spinal cord lesions. *J Rehabil Med* 2005;37(1):9-16.
- (40) Kreuter M, Sjösteen A, Erholm B, Byström U, Brown DJ. Health and quality of life of persons with spinal cord lesion in Australia and Sweden. *Spinal Cord* 2005;43(2):123-9.

- (41) Marino RJ, Barros T, Biering-Sørensen F, Burns SP, Donovan WH, Graves DE, et al. International standards for neurological classification of spinal cord injury. *J Spinal Cord Med* 2003;26 (suppl. 1):S50-S56.
- (42) Frankel HL, Hancock Do, Hyslop G, Melzak J, Michaelis LS, Ungar GH, et al. The value of postural reduction in the initial management of closed injuries of the spine with paraplegia and tetraplegia. *Paraplegia* 1969;7(3):179-92.
- (43) DeVivo M, Biering-Sørensen F, Charlifue S, Noonan V, Post M, Stripling T, et al. International Spinal Cord Injury Core Data Set. *Spinal Cord* 2006;44(9):534-40. Review.
- (44) DeVivo MJ. Sir Ludwig Guttmann Lecture: Trends in spinal cord injury rehabilitation outcomes from model systems in the United States: 1973-2006. *Spinal Cord* 2007;45(11):713-21.
- (45) Garshick E, Kelley A, Cohen SA, Garrison A, Tun CG, Gagnon D, et al. A prospective assessment of mortality in chronic spinal cord injury. *Spinal Cord* 2005;43(7):408-16.
- (46) Krause JS, Carter RE, Pickelsimer E. Behavioural risk factors of mortality after spinal cord injury. *Arch Phys Med Rehabil* 2009;90(1):95-101.
- (47) Giaquinto S, Ring H. Return to work in selected disabilities. *Disabil Rehabil* 2007;29(17):1313-16.
- (48) O'Connor PJ. Survival after spinal cord injury in Australia. *Arch Phys Med Rehabil* 2005;86(1):37-47.
- (49) DeVivo MJ, Krause JS, Lammertse DP. Recent trends in mortality and causes of death among persons with spinal cord injury. *Arch Phys Med Rehabil* 1999;80(11):1411-9.
- (50) DeVivo MJ, Rutt RD, Black KJ, Go BK, Stover SL. Trends in spinal cord injury demographics and treatment outcomes between 1973 and 1986. *Arch Phys Med Rehabil* 1992;73(5):424-30.
- (51) McColl MA, Walker J, Stirling P, Wilkins R, Corey P. Expectations of life and health among spinal cord injured adults. *Spinal Cord* 1997;35(12):818-28.
- (52) Strauss DJ, DeVivo MJ, Paculdo DR, Shavelle RM. Trends in life expectancy after spinal cord injury. *Arch Phys Med Rehabil* 2006;87(8):1079-85.
- (53) DeVivo MJ, Stover SL, Black KJ. Prognostic factors for 12-year survival after spinal cord injury. *Arch Phys Med Rehabil* 1992;73(2):156-62.
- (54) Yeo JD, Walsh J, Rutkowski S, Soden R, Craven M, Middleton J. Mortality following spinal cord injury. *Spinal Cord* 1998;36(5):329-36.

- (55) Kiwerski JE. Factors contributing to the increased threat to life following spinal cord injury. *Paraplegia* 1993;31(12):793-9.
- (56) Krause JS, Sternberg M, Lottes S, Maides J. Mortality after spinal cord injury: an 11-year prospective study. *Arch Phys Med Rehabil* 1997;78(8):815-21.
- (57) Krause JS, Carter R, Zhai Y, Reed K. Psychologic factors and risk of mortality after spinal cord injury. *Arch Phys Med Rehabil* 2009;90(4):628-33.
- (58) Krause JS, Zhai Y, Saunders LL, Carter RE. Risk of mortality after spinal cord injury: an 8-year prospective study. *Arch Phys Med Rehabil* 2009;90(10):1708-15.
- (59) DeVivo MJ, Black KJ, Stover SL. Causes of death during the first 12 years after spinal cord injury. *Arch Phys Med Rehabil* 1993;74(3):248-54.
- (60) Nakajima A, Honda S, Yoshimura S, Ono Y, Kawamura J, Moriai N. The disease pattern and causes of death of spinal cord injured patients in Japan. *Paraplegia* 1989;27(3):163-71.
- (61) Soden R, Walsh J, Middleton JW, Craven ML, Rutkowski SB, Yeo JD. Causes of death after spinal cord injury. *Spinal Cord* 2000;38(10):604-10.
- (62) Hartkopp A, Brønnum-Hansen H, Seidenschneur A-M, Biering-Sørensen F. Suicide in a spinal cord injured population: its relation to functional status. *Arch Phys Med Rehabil* 1998;79(11):1356-61.
- (63) Veenstra M. Personal troubles and public issues: measuring patient-reported outcomes in chronic illness 2006. Oslo, Norway: The Faculty of Medicine, Department of Behavioural Sciences in Medicine, University of Oslo; 2006.
- (64) Alexander MS, Anderson KD, Biering-Sørensen F, Blight AR, Brannon R, Bryce TN, et al. Outcome measures in spinal cord injury: recent assessments and recommendations for future directions. *Spinal Cord* 2009;47(8):582-91. Review.
- (65) The world health organization quality of life assessment (WHOQOL): position paper from the World Health Organization. *Soc Sci Med* 1995;41(10):1403-9.
- (66) Dijkers MPJM. Quality of life of individuals with spinal cord injury: a review of conceptualization, measurement, and research findings. *J Rehabil Res Dev* 2005;42(3):87-110. Review.
- (67) Post M, Noreau L. Quality of life after spinal cord injury. *J Neurol Phys Ther* 2005;29(3):139-46.

- (68) Tate DG, Kalpakjian CZ, Forchheimer MB. Quality of life issues in individuals with spinal cord injury. *Arch Phys Med Rehabil* 2002;83(12 Suppl 2):S18-25.
- (69) Wilson IB, Cleary PD. Linking clinical variables with health-related quality of life. A conceptual model of patient outcomes. *JAMA* 1995;273(1):59-65.
- (70) Wood-Dauphinée S, Exner G, Bostanci B, Glass C, Jochheim KA, Kluger P, et al. Quality of life in patients with spinal cord injury - basic issues, assessment, and recommendations. *Restor Neurol Neurosci* 2002; 20 (3-4):135-49. Review.
- (71) Leduc BE, Lepage Y. Health-related quality of life after spinal cord injury. *Disabil Rehabil* 2002;24(4):196-202.
- (72) Haran MJ, Lee BB, King MT, Marial O, Stockler MR. Health status rated with the Medical Outcomes Study 36-Item Short-Form Health Survey after spinal cord injury. *Arch Phys Med Rehabil* 2005;86(12):2290-5.
- (73) Andresen EM, Fouts BS, Romeis JC, Brownson CA. Performance of health-related quality-of-life instruments in a spinal cord injured population. *Arch Phys Med Rehabil* 1999;80(8):877-84.
- (74) Ku JH. Health-related quality of life in patients with spinal cord injury: review of the Short Form 36-Health Questionnaire Survey. *Yonsei Med J* 2007;48(3):360-70. Review.
- (75) Johnson RL, Gerhart KA, McCray J, Menconi JC, Whiteneck GG. Secondary conditions following spinal cord injury in a population-based sample. *Spinal Cord* 1998;36(1):45-50.
- (76) Bloemen-Vrencken JHA, Post MWM, Hendriks JMS, De Reus ECE, de Witte LP. Health problems of persons with spinal cord injury living in the Netherlands. *Disabil Rehabil* 2005;27(22):1381-9.
- (77) Noreau L, Proulx P, Gagnon L, Drolet M, Laramée MT. Secondary impairments after spinal cord injury: a population-based study. *Am J Phys Med Rehabil* 2000;79(6):526-35.
- (78) Hitzig SL, Tonack M, Campbell KA, McGillivray CF, Boschen KA, Richards K, et al. Secondary health complications in an aging Canadian spinal cord injury sample. *Am J Phys Med Rehabil* 2008;87(7):545-55.
- (79) Dunn M, Love L, Ravessloot C. Subjective health in spinal cord injury after outpatient healthcare follow-up. *Spinal Cord* 2000;38(2):84-91.
- (80) Krahn GL, Suzuki R, Horner-Johnson W. Self-rated health in persons with spinal cord injury: relationship of secondary conditions, function and health status. *Qual Life Res* 2009;18(5):575-84.

- (81) Turk MA. Secondary conditions and disability
In:Field MJ, Jette AM, Kartin L, editors. Workshop on disability in America: a new look. Washington (DC): Natl Acad Pr. 2006. p. 185-93.
- (82) Charlifue SW, Weitzenkamp DA, Whiteneck GG. Longitudinal outcomes in spinal cord injury: aging, secondary conditions, and well-being. *Arch Phys Med Rehabil* 1999;80(11):1429-34.
- (83) McKinley WO, Jackson AB, Cardenas DD, DeVivo MJ. Long-term medical complications after traumatic spinal cord injury: a regional model system analysis. *Arch Phys Med Rehabil* 1999;80(11):1402-10.
- (84) Middleton J, Lim K, Taylor L, Soden R, Rutkowski S. Patterns of morbidity and rehospitalizations following spinal cord injury. *Spinal Cord* 2004;42(2):359-67.
- (85) Cardenas DD, Hoffman JM, Kirshblum S, McKinley W. Etiology and incidence of rehospitalization after traumatic spinal cord injury: a multicenter analysis. *Arch Phys Med Rehabil* 2004;85(11):1757-63.
- (86) Noonan VK, Kopec JA, Zhang H, Dvorak MF. Impact of associated conditions resulting from spinal cord injury on health status and quality of life in people with traumatic central cord syndrome. *Arch Phys Med Rehabil* 2008;89(6):1074-82.
- (87) Krause JS. Skin sores after spinal cord injury: relationship to life adjustment. *Spinal Cord* 1998;36(1):51-6.
- (88) Charlifue S, Lammertse DP, Adkins RH. Aging with spinal cord injury: changes in selected health indices and life satisfaction. *Arch Phys Med Rehabil* 2004;85(11):1848-53.
- (89) Pentland W, Harvey AS, Smith T, Walker J. The impact of spinal cord injury on men's time use. *Spinal Cord* 1999;37(11):786-92.
- (90) Young AE, Murphy GC. A social psychology approach to measuring vocational rehabilitation intervention effectiveness. *J Occup Rehabil* 2002;12(3):175-89.
- (91) Meade MA, Lewis A, Jackson MN, Hess DW. Race, employment, and spinal cord injury. *Arch Phys Med Rehabil* 2004;85(11):1782-92.
- (92) Krause JS, Terza JV, Dismuke C. Earnings among people with spinal cord injury. *Arch Phys Med Rehabil* 2008;89(8):1474-81.
- (93) Dowler R, Richards JS, Putzke JD, Gordon W, Tate D. Impact of demographic and medical factors on satisfaction with life after spinal cord injury: a normative study. *J Spinal Cord Med* 2001;24(2):87-91.
- (94) Hess DW, Meade MA, Forchheimer M, Tate DG. Psychological well-being and intensity of employment in individuals with a spinal cord injury. *Top Spinal Cord Inj Rehabil* 2004;9(4):1-10.

- (95) Putzke JD, Richards JS, Hicken BL, DeVivo MJ. Predictors of life satisfaction: a spinal cord injury cohort study. *Arch Phys Med Rehabil* 2002;83(4):555-61.
- (96) Chan SKK, Man DWK. Barriers to returning to work for people with spinal cord injuries: a focus group study. *Work* 2005;25(4):325-32.
- (97) Mitchell JM, Adkins RH, Kemp BJ. The effect of aging on employment of people with and without disabilities. *Rehabil Counsel Bull* 2006;49(3):157-65.
- (98) DeVivo MJ, Rutt RD, Stover SL, Fine PR. Employment after spinal cord injury. *Arch Phys Med Rehabil* 1987;68(8):494-8.
- (99) Krause JS, Sternberg M, Maides J, Lottes S. Employment after spinal cord injury: differences related to geographic region, gender and race. *Arch Phys Med Rehabil* 1998;79(6):615-24.
- (100) Krause JS, Broderick L. A 25-year longitudinal study of the natural course of aging after spinal cord injury. *Spinal Cord* 2005;43(6):349-56.
- (101) Krause JS. Employment after spinal cord injury. *Arch Phys Med Rehabil* 1992;73(2):163-9.
- (102) Krause JS. Years to employment after spinal cord injury. *Arch Phys Med Rehabil* 2003;84(9):1282-9.
- (103) Young AE, Murphy GC. Employment status after spinal cord injury (1992-2005): a review with implications for interpretation, evaluation, further research, and clinical practice. *Int J Rehabil Res* 2009;32(1):1-11. Review.
- (104) Jongbloed L, Backman C, Forwell SJ, Carpenter C. Employment after spinal cord injury: the impact of government policies in Canada. *Work* 2007;29(2):145-54.
- (105) Valtonen K, Karlsson AK, Alaranta H, Viikari-Juntura E. Work participation among persons with traumatic spinal cord injury and meningomyelocele. *J Rehabil Med* 2006;38(3):192-200.
- (106) Dijkers M. Measuring quality of life: methodological issues. *Am J Phys Med Rehabil* 1999;78(3):286-300. Review.
- (107) Fugl-Meyer AR, Bränholm IB, Fugl-Meyer KS. Happiness and domain-specific life satisfaction in adult northern Swedes. *Clin Rehabil* 1991;5(1):25-33.
- (108) Price GL, Kendall M, Amsters DI, Pershouse KJ. Perceived causes of change in function and quality of life for people with long duration spinal cord injury. *Clin Rehabil* 2004;18(2):164-71.

- (109) Putzke JD, Barrett JJ, Richards JS, Underhill AT, LoBello SG. Life satisfaction following spinal cord injury: long-term follow-up. *J Spinal Cord Med* 2004;27(2):106-10.
- (110) Budh CN, Osteråker AL. Life satisfaction in individuals with a spinal cord injury and pain. *Clin Rehabil* 2007;21(1):89-96.
- (111) Athanasou JA, Brown DJ, Murphy GC. Vocational achievements following spinal cord injury in Australia. *Disabil Rehabil* 1996;18(4):191-6.
- (112) Yasuda S, Wehman P, Targett P, Cifu DX, West M. Return to work after spinal cord injury: a review of recent research. *NeuroRehabilitation* 2002;17(3):177-86. Review.
- (113) Higgins JPT, Green S. Cochrane handbook for systematic reviews of interventions. <http://www.cochrane-handbook.org> 2008 (Version 5.0.1)
- (114) Dijkers MPJM, Task Force on Systematic Reviews and Guidelines. The value of "traditional" reviews in the era of systematic reviewing. *Am J Phys Med Rehabil* 2009;88(5):423-30.
- (115) Cook DJ, Mulrow CD, Haynes RB. Systematic reviews: synthesis of best evidence for clinical decisions. *Ann Intern Med* 1997;126(5):376-80.
- (116) Wright RW, Brand RA, Dunn W, Spindler KP. How to write a systematic review. *Clin Orthop Rel Res* 2007;455:23-9.
- (117) Norwegian Social Science Data Services (NSD). The Norwegian Survey Archive. <http://www.nsd.uib.no/english/> 2006
- (118) Altman DG. Practical statistics for medical research. First ed. London: Chapman & Hall; 1991.
- (119) Pedersen AG. A survey of the Cause of Death Registry and the existing rules to establish codes 1996-1997. 2000. (Norwegian)
- (120) Pedersen AG, Strøm K, Østevold G, Hoff J, Djume W, Westby G. Causes of death 1991-2000. Official Statistics of Norway; 2003.
- (121) Centers for Disease Control and Prevention. Instruction manual part 2b. Instructions for classifying multiple causes of death. <http://www.cdc.gov/nchs/data/dvs/2b> Final pdf 2008 January 1:1-443.
- (122) About the WHO mortality data. <http://www.who.int/healthinfo/statistics/mortdata/en/>. 2009
- (123) Krokstad S, Ringdal K, Westin S. Classifying people by social class in population based health surveys: Two methods compared. *Norwegian Epidemiology* 2002;12:19-25.

- (124) Krokstad S, Westin S. Health inequalities by socioeconomic status among men in the Nord-Trøndelag Health Study, Norway. *Scand J Public Health* 2002;30(2):113-24.
- (125) Forchheimer M, McAweeney M, Tate DG. Use of the SF-36 among persons with spinal cord injury. *Am J Phys Med Rehabil* 2004;83(5):390-5.
- (126) Ware JE, Sherbourne CD. The MOS 36-Item Short-Form Health Survey (SF-36) I. Conceptual framework and item selection. *Med Care* 1992;30(6):473-83.
- (127) Ware JE. The SF-36 Health Survey. In: Spilker B, editor. *Quality of Life and Pharmacoeconomics in Clinical Trials*. Second Edition ed. Philadelphia: Lippincott-Raven Publishers; 1996. p. 337-43.
- (128) McHorney CA, Ware JE, Raczek A. The MOS 36-Item Short-Form Health Survey (SF-36): II. Psychometric and clinical tests of validity in measuring physical and mental health constructs. *Med Care* 1993;31(3):247-63.
- (129) McHorney CA, Ware JE, Rogers W, Raczek AE, Lu JFR. The validity and relative precision of MOS short- and long- form health status scales and Dartmouth COOP Charts. *Med Care* 1992;30(5 Suppl):MS253-65.
- (130) Loge JH, Kaasa S, Hjermsstad MJ, Kvien TK. Translation and performance of the Norwegian SF-36 Health Survey in patients with rheumatoid arthritis. I. Data quality, scaling assumptions, reliability, and construct validity. *J Clin Epidemiol* 1998;51(11):1069-76.
- (131) Loge JH, Kaasa S. Short form 36 (SF-36) health survey: normative data from the general Norwegian population. *Scand J Soc Med* 1998;26(4):250-8.
- (132) How to score the SF-36 Health Survey. Boston: 1993.
- (133) Fugl-Meyer AR, Melin R, Fugl-Meyer K. Life satisfaction in 18- to 64-year-old Swedes: in relation to gender, age, partner and immigrant status. *J Rehabil Med* 2002;34(5):239-46.
- (134) Melin R, Fugl-Meyer K, Fugl-Meyer AR. Life satisfaction in 18- to 64-year-old Swedes: in relation to education, employment situation, health and physical activity. *J Rehabil Med* 2003;35(2):84-90.
- (135) Schonherr MC, Groothoff JW, Mulder GA, Eisma WH. Participation and satisfaction after spinal cord injury: results of a vocational and leisure outcome study. *Spinal Cord* 2005;43(4):241-8.
- (136) Post MW, de Witte LP, van Asbeck FWA, van Dijk AJ, Schrijvers AJ. Predictors of health status and life satisfaction in spinal cord injury. *Arch Phys Med Rehabil* 1998;79(4):395-402.

- (137) Anke AGW. Bio-psycho-social aspects of severe multiple trauma
University Hospital of North Norway, Tromsø, Norway; 2003.
- (138) Hjermland MJ, Fayers PM, Bjordal K, Kaasa S. Using reference data on quality of life - the importance of adjusting for age and gender, exemplified by the EORTC QLQ-C30(+3). *Eur J Cancer* 1998;34(9): 1381-9.
- (139) Rosenthal R, Rosnow RL. *Essentials of behavioural research: Methods and data analysis.* (2nd ed.) ed. New York: McGraw Hill; 1991.
- (140) Cohen J. A power primer. *Psychol Bull* 1992;112(1):155-9.
- (141) Hosmer DW, Lemeshow S. *Applied logistic regression.* Second ed. Massachusetts; Ohio: Wiley interscience; 2000.
- (142) Akaike H. A new look at the statistical model identification. *IEEE Transactions on Automatic Control* 1974;19(6):716-23.
- (143) World medical association declaration of Helsinki. Ethical Principles for Medical Research Involving Human Subjects.
<http://www.wma.net/en/30publications/10policies/b3/index.html> 2008
- (144) Rigby AS. Statistical reviewing for disability and rehabilitation. *Disabil Rehabil* 2009;31(7):515-21. Review.
- (145) Jahnsen R. Being adult with a "childhood disease" - a survey on adults with cerebral palsy in Norway. Oslo, Norway: The Faculty of Medicine, Section for Health Science, University of Oslo; 2004.
- (146) Streiner DL, Norman GR. *Biases in responding. Health measurement scales: a practical guide to their development and use.* Third ed. Oxford University Press; 2002. p. 80-101.
- (147) Dagfinrud H. *Ankylosing spondylitis: Disease impact and research evidence of physiotherapy interventions.* Oslo, Norway: The Faculty of Medicine, Section for Health Science, University of Oslo; 2005.
- (148) Bowling A, Bond M, Jenkinson C, Lamping DL. Short form 36 (SF-36) Health Survey questionnaire: which normative data should be used? Comparisons between the norms provided by the Omnibus Survey in Britain, the Health Survey for England and the Oxford Healthy Life Survey. *J Public Health* 1999;21(3):255-70.
- (149) Rothman KJ, Greenland S. *Precisions and validity in epidemiologic studies.* Modern epidemiology. Second ed. 1998. p. 115-34.
- (150) Krause JS, Kewman D, DeVivo MJ, Maynard FM, Coker J, Roach MJ, et al. Employment after spinal cord injury: an analysis of cases from the Model Spinal Cord Injury Systems. *Arch Phys Med Rehabil* 1999;80(11):1492-500.

- (151) Keller SD, Ware JE, Bentler PM, Aaronson NK, Alonso J, Apolone G, et al. Use of structural equation modeling to test the construct validity of the SF-36 Health Survey in ten countries: results from the IQOLA Project. *International Quality of Life Assessment. J Clin Epidemiol* 1998;51(11):1179-88.
- (152) Jain NB, Sullivan M, Kazis LE, Tun CG, Garshick E. Factors associated with health-related quality of life in chronic spinal cord injury. *Am J Phys Med Rehabil* 2007;86(5):387-96.
- (153) Lundqvist C, Siösteen A, Sullivan L, Blomstrand C, Lind B, Sullivan M. Spinal cord injuries: a shortened measure of function and mood. *Spinal Cord* 1997;35(1):17-21.
- (154) Lee BB, Simpson JM, King MT, Haran MJ, Marial O. The SF-36 walk-wheel: a simple modification of the SF-36 physical domain improves its responsiveness for measuring health status change in spinal cord injury. *Spinal Cord* 2009;47(1):50-5.
- (155) Fugl-Meyer AR, Eklund M, Fugl-Meyer KS. Vocational rehabilitation in northern Sweden. III. Aspects of life satisfaction. *Scand J Rehabil Med* 1991;23(2):83-7.
- (156) Kennedy P, Lude P, Taylor N. Quality of life, social participation, appraisals and coping post spinal cord injury: a review of four community samples. *Spinal Cord* 2006;44(2):95-105.
- (157) Anke AGW, Fugl-Meyer AR. Life satisfaction several years after severe multiple trauma - a retrospective investigation. *Clin Rehabil* 2003;17(4):431-42.
- (158) Shavelle RM, DeVivo MJ, Strauss DJ, Paculdo DR, Lammertse DP, Day SM. Long-term survival of persons ventilator dependent after spinal cord injury. *J Spinal Cord Med* 2006;29(5):511-9.
- (159) Le CT, Price M. Survival from spinal cord injury. *J Chronic Dis* 1982;35:487-92.
- (160) Statistics Norway. The most common causes of death. 2004. <http://www.ssb.no/samfunnsspeilet/utg/200703/03/tab-2007-06-19-02.html> (Norwegian).
- (161) Waites KB, Canupp KC, Chen Y, DeVivo M.J., Nahm MH. Revaccination of adults with spinal cord injury using theb23-valent pneumococcal polysaccharide vaccine. *J Spinal Cord Med* 2007;31(1):53-9.
- (162) Bauman WA, Kahn NN, Grimm DR, Spungen AM. Risk factors for atherogenesis and cardiovascular autonomic function in persons with spinal cord injury. *Spinal Cord* 1999;37(9):601-16.

- (163) Krassioukov A, Claydon VE. The clinical problems in cardiovascular control following spinal cord injury: an overview. *Prog Brain Res* 2006;152:223-9.
- (164) Myers J, Lee M, Kiratli J. Cardiovascular disease in spinal cord injury: an overview of prevalence, risk, evaluation, and management. *Am J Phys Med Rehabil* 2007;86(2):142-52. Review.
- (165) Aksnes AK, Hjeltnes N, Wahlström EÖ, Katz A, Zierath JR, Wallberg-Henriksson H. Intact glucose transport in morphologically altered denervated skeletal muscle from quadriplegic patients. *Am J Physiol* 1996;271(3 Pt 1):E593-600.
- (166) Groah SL, Weitzenkamp D, Whiteneck GG, Lezotte DC, Hamman RF. Excess risk of bladder cancer in spinal cord injury: evidence for an association between indwelling catheter use and bladder cancer. *Arch Phys Med Rehabil* 2002;83(3):346-51.
- (167) Kalisvaart JF, Katsumi HK, Ronningen LD, Hovey RM. Bladder cancer in spinal cord injury patients. *Spinal Cord* 2009;Sep 15 (Epub ahead of print):1-5.
- (168) Cavanagh JTO, Carson AJ, Sharpe M, Lawrie SM. Psychological autopsy studies of suicide: a systematic review. *Psychol Med* 2003;33(3):395-405. Review.
- (169) Grøholt B. Risk factors for suicidal behaviour among young people in Norway. *Norwegian Epidemiology* 2002;12:207-14. (Norwegian)
- (170) Kjølsest I, Ekeberg Ø, Teige B. Elderly suicide in Norway. *Tidsskr Nor Lægeforen* 2002;122:1457-61. (Norwegian)
- (171) DeVivo MJ, Kartus PL, Stover SL, Rutt RD, Fine PR. Causes of death for patients with spinal cord injuries. *Arch Intern Med* 1989;149(8):1761-6.
- (172) DeVivo MJ, Black KJ, Richards JS, Stover SL. Suicide following spinal cord injury. *Paraplegia* 1991;29(9):620-7.
- (173) Krause JS, Carter R, Pickelsimer EE, Wilson D. A prospective study of health and risk of mortality after spinal cord injury. *Arch Phys Med Rehabil* 2007;89(8):1482-91.
- (174) Krause JS, Carter RE. Risk of mortality after spinal cord injury: relationship with social support, education, and income. *Spinal Cord* 2009;47(8):592-6.
- (175) Glesby MJ, Hoover DR. Survivor treatment selection bias in observational studies: examples from the AIDS literature. *Intern Med* 1996;124(11):999-1005.

- (176) Tate DG, Riley BB, Perna R, Roller S. Quality of life issues among women with physical disabilities or breast cancer. *Arch Phys Med Rehabil* 1997;78(12 Suppl):S18-25.
- (177) Tate DG, Forchheimer M. Quality of life, life satisfaction, and spirituality: comparing outcomes between rehabilitation and cancer patients. *Am J Phys Med Rehabil* 2002;81(6):400-10.
- (178) Lucas JT, Ducker TB. Motor classification of spinal cord injuries with mobility, morbidity and recovery indices. *The American Surgeon* 1979;(151):158.
- (179) Oh JS, Ku JH, Jeon HG, Shin HI, Paik NJ, Yoo T. Health-related quality of life of patients using clean intermittent catheterization for neurogenic bladder secondary to spinal cord injury. *Urology* 2005;65(2):306-10.
- (180) Celic B, Gultekin O, Beydogan A, Caglar N. Domain-specific quality of life assessment in spinal cord injured patients. *Int J Rehabil Res* 2007;30(2):97-101.
- (181) Anke AG, Stenehjem AE, Stanghelle JK. Pain and life quality within 2 years of spinal cord injury. *Paraplegia* 1995;33(10):555-9.
- (182) Dijkers M, Bryce T, Zanca J. Prevalence of chronic pain after traumatic spinal cord injury: a systematic review. *J Rehabil Res Dev* 2009;46(1):13-30. Review.
- (183) Krause JS, Coker JL. Aging after spinal cord injury: A 30-year longitudinal study. *J Spinal Cord Med* 2006;29(4):371-6.
- (184) Pflaum C, McCollister G, Strauss DJ, Shavelle RM, DeVivo MJ. Worklife after traumatic spinal cord injury. *J Spinal Cord Med* 2006;29(4):377-86.
- (185) Hess DW, Ripley DL, McKinley WO, Tewksbury M. Predictors for return to work after spinal cord injury: a 3-year multicenter analysis. *Arch Phys Med Rehabil* 2000;81(3):359-63.
- (186) Jang Y, Wang YH, Wang JD. Return to work after spinal cord injury in Taiwan: the contribution of functional independence. *Arch Phys Med Rehabil* 2005;86(4):681-6.
- (187) Krause JS, Terza JV. Injury and demographic factors predictive of disparities in earnings after spinal cord injury. *Arch Phys Med Rehabil* 2006;87(10):1318-26.
- (188) Tomassen PC, Post MW, van Asbeck FW. Return to work after spinal cord injury. *Spinal Cord* 2000 Jan;38(1):51-5.
- (189) Murphy G, Middleton J, Quirk R, De Wolf A, Cameron ID. Prediction of employment status one year post-discharge from rehabilitation following spinal cord injury: an exploratory analysis of participation and environmental variables. *J Rehabil Med* 2009;41(13):1074-9.

- (190) Arango-Lasprilla JC, Ketchum JM, Stevens LF, Balcazar F, Wehman P, Forster L, et al. Ethnicity/racial differences in employment outcomes following spinal cord injury. *NeuroRehabilitation* 2009;24(1):37-46.
- (191) Kurtaran A, Akbal A, Ersöz M, Selçuk B, Yalçın E, Akyüz M. Occupation in spinal cord injury patients in Turkey. *Spinal Cord* 2009;47(9):709-12.
- (192) Lin MR, Hwang HF, Yu WY, Chen CY. A prospective study of factors influencing return to work after traumatic spinal cord injury in Taiwan. *Arch Phys Med Rehabil* 2009;90(10):1716-22.
- (193) van Velzen JM, de Groot S, Post MWM, Slootman JR, van Bennekom CAM, van der Woude LHV. Return to work after spinal cord injury: is it related to wheelchair capacity at discharge from clinical rehabilitation? *Am J Phys Med Rehabil* 2009;88(1):47-56.
- (194) Fadyl JK, McPherson KM. Understanding decisions about work after spinal cord injury. *J Occup Rehabil* 2009, Published online sept. 2009
- (195) Rowell D, Connelly LB. Personal assistance, income and employment: the spinal injuries survey instrument (SISI) and its application in a sample of people with quadriplegia. *Spinal Cord* 2008;46(6):417-24.
- (196) Isaksson G, Josephsson S, Lexell J, Skär L. To regain participation in occupation through human encounters - narratives from women with spinal cord injury. *Disabil Rehabil* 2007;29(22):1679-88.
- (197) Nordgren C, Levi R, Ljunggren G, Seiger Å. Societal services after traumatic spinal cord injury in Sweden. *J Rehabil Med* 2003;35(3):121-6.
- (198) Statistics Norway. 45 per cent of disabled people employed. Labour force survey. Ad hoc module on disabled people, 2nd quarter 2008. http://www.ssb.no/english/subjects/06/01/akutu_en/2008
- (199) The Norwegian Association of Disabled. Employment. <http://www.nhf.no/> 2009 March 25. (Norwegian)

8. PAPERS I – IV

ORIGINAL REPORT

MORTALITY AFTER SPINAL CORD INJURY IN NORWAY

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Objectives: To study mortality, cause of death and risk indicators for death in Norwegian patients with spinal cord injury.

Design: A cross-sectional study with retrospective data.

Subjects: All patients ($n=387$) with traumatic spinal cord injury admitted to Sunnaas Rehabilitation Hospital, Norway, during the period 1961–82.

Methods: Medical records were reviewed retrospectively. Causes of death were collected from Statistics Norway and death certificates. Standardized mortality ratios (SMRs) were calculated for the entire sample and for causes of death. To explore risk indicators for death, a Cox regression model was used.

Results: During the observation period, 1961–2002, 142 patients died. The main causes of death were pneumonia/influenza (16%), ischaemic heart diseases (13%) and urogenital diseases (13%). SMR was 1.8 for men and 4.9 for women. Cause-specific SMRs were markedly elevated for urogenital diseases, suicide, pneumonia/influenza, urogenital cancer, and diseases of the digestive system. Risk indicators for death were: higher age at injury, tetraplegia, functionally complete spinal cord injury, pre-injury cardiovascular disease, alcohol or substance abuse and psychiatric diagnosis.

Conclusion: The SMRs show that life expectancy is reduced in chronic spinal cord injury in Norway, more for women than for men. Cause-specific SMRs and risk indicators suggest that the high mortality rates after spinal cord injury to a certain degree are related to preventable aetiologies. To maximize longevity in chronic spinal cord injury, more attention must be paid to co-morbidity.

Key words: spinal cord injury, mortality, causes of death, epidemiology, risk indicators.

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INTRODUCTION

Causes of death in spinal cord injury (SCI) have changed, from being primarily urinary tract disease (1–5) to, increasingly,

cardiovascular disease (CVD) (mainly ischaemic heart disease) (1, 3, 6–10) and respiratory complications (1, 3, 6–8, 10–14), thus becoming similar to the causes of death in the general population. Improved early medical care, specialized rehabilitation and regular follow-up visits have contributed to this development. However, the longevity of persons with SCI still remains below that of the general population (1, 2, 4–9, 15–19). Several analyses on mortality have found that important risk indicators for death in this group include the neurological level of injury (1–3, 7, 12, 15–17, 19–21), completeness of the SCI (1–4, 7, 15, 17, 19–22), older age at injury (1–3, 9, 12, 15–17, 19–21) and the risk of death is highest during the first year(s) post-injury (1, 15–17, 19).

There is a lack of previous studies on mortality of SCI in Norway. However, the social welfare system, covering all people in society, makes it possible to perform such studies. The aims of the present study were to compare survival in persons with SCI with survival in the general population, causes of death, and to explore predictors of eventual early death in SCI.

METHODS

Material

A total of 396 persons with traumatic SCI were admitted to Sunnaas Rehabilitation Hospital between 1961 and 1982 inclusive. According to the annual incidence of traumatic SCI in Norway, the sample represents approximately 25–30% of all new cases of SCI from this period. The patient selection to Sunnaas was not 100% from specific areas of Norway in any year. The main proportion of persons enrolled, were resident in eastern or southern areas of Norway (i.e. 68% of the total sample). However, patients from all areas of the country are represented.

Four patients who died within one year post-injury were excluded. One patient was omitted due to lack of vital data, and another 4 patients could not be identified. The remaining 387 persons (321 men and 66 women) survived at least one year following injury and were included in this retrospective study. All subjects were at least 20 years post-injury when the study was performed. Dates of death were registered until 31 December 2002.

Data collection

Information on the vital status of the observed population was obtained from The Central Population Register of Norway. This register contains vital data for all Norwegian citizens, including date of birth, residence and date of death. A personal 11-digit number makes it possible to identify any Norwegian citizen. The survival status of 8

persons who emigrated from Norway could not be determined. These subjects were censored at their last known date alive. Vital data for the general population from the study period was obtained from Statistics Norway.

The "underlying cause of death" is used in the international cause of death statistics. To determine the causes of death we collected information from 2 sources: (i) the Cause of Death Register, Statistics Norway; (ii) death certificates. Information on the underlying cause of death used in the Cause of Death Register is based primarily on medical death certificates (23, 24). The underlying cause of death gives more prominence to the external cause of the injury-producing event (19), i.e. in many cases the injuries that caused the SCIs, rather than to the direct/immediate causes of death. For this reason, we decided to recode the cases where the injury that caused the SCI was listed as the underlying cause of death. In these situations, we extracted information from the death certificates as follows: We coded the next cause listed in the death certificate as the underlying cause of death, instead of the original cause noted in the Cause of Death Register. Only in the cases of new accidents, i.e. new events subsequent to the SCI, were "Unintentional injuries" (ICD-9 E800-E949) recorded as the underlying cause of death. In addition, the underlying causes of death in Norwegian men and women through the years 1961 to 2002 inclusive were obtained from the Cause of Death Register (23, 25, 26). ICD-9 (International Classification of Diseases - 9th Edition Clinical Modification) was used to classify diseases causing death. Deaths classified according to ICD-7, ICD-8 and ICD-10 revisions were translated to ICD-9.

Information extracted from each patients' medical record included demographic data, occupational status, prevalence of pre-injury medical conditions, date of admission and discharge from the rehabilitation hospital, injury-related data including associated injuries caused by the accident, neurological level of injury (grouped into tetraplegia, i.e. cervical spinal cord lesions, or paraplegia, i.e. thoracic and lumbarsacral lesions), Frankel classification (merged into 2 groups, i.e. Frankel A-C and D-E) (27) and post-injury secondary medical complications. Occupational classification was determined by a modified version of the Erikson Goldthorpe Portocarero social class scheme (28, 29) and included 10 categories. Retired persons were classified according to their former occupation. Persons younger than 16 years were excluded from analysis that included occupational classification. Pre-injury medical diseases were categorized into 6 groups according to the most frequent diagnoses.

The material was dichotomized into 2 incidence groups according to the time of injury, i.e. 1961-75 or 1976-82. This was done because the SCI-rehabilitation gradually became organized as a specialized unit with multidisciplinary teams from the early to mid-1970s.

The study was approved by The Regional Ethics Committee, Oslo, Norway.

Statistical analysis

Descriptive statistics were generated, including medians, percentages and frequencies in order to emphasize the actual numbers. The *t*-test and the Mann-Whitney *U* test were performed where appropriate. χ^2 methods were applied to compare categorical variables. Standardized mortality ratios (SMRs) were computed for gender, tetraplegia/paraplegia and 2 incidence periods (1961-75 and 1976-82). SMR is the actual mortality in the observed population divided by the expected mortality in the general population occurring during the specified time interval of the study. If the SMR exceeds 1.0, the mortality rate in the study population was larger than expected. An estimated SMR of 2.0 indicates that twice as many deaths occurred in the study population. Accordingly, SMRs for selected causes of death were calculated. The expected numbers of deaths were estimated using age-gender-specific rates for the selected diagnoses.

Risk indicators and relative risk estimates associated with death were estimated by means of a Cox regression model. First, the relationship between each potential explanatory variable and the outcome variable of interest, i.e. the time interval from entry into the study (at the time of

injury) until death or point censored, was examined. A criterion level of $p < 0.25$ for inclusion in the final model was chosen. Next, a forward selection procedure was used to fit the adjusted model (30).

Kaplan-Meier curves were used to visualize survival by age at death or censoring of the studied SCI population compared with the general population. Further, Kaplan-Meier curves were used to show time from injury until death or censoring for patients injured in the periods 1961-75 ($n=198$) and 1976-82 ($n=189$). A log-rank test was carried out to compare survival between the 2 incidence periods, and included all subjects. The algorithms in Statistical Packages for the Social Sciences (SPSS) version 11.5 were used in all calculations. *p*-values less than 0.05 were considered statistically significant.

RESULTS

Population

Table I presents the study population ($n=387$) divided into tetraplegia and paraplegia, respectively. Persons with tetraplegia were significantly older at injury and included more men. A higher proportion of functionally incomplete SCI appeared among persons with tetraplegia compared with persons with lower lesions. The aetiology was transport accidents in 46% of all cases, most frequently traffic injuries. Fall accidents and assaults were more common in persons with paraplegia, while sports accidents were seen more often in persons with tetraplegia. Frequent associated injuries were traumas of the head (25% of the total sample) and other bone fractures (23%

Table I. Characteristics of all patients with traumatic spinal cord injury (SCI) included in the study, divided by the neurological level of lesion (tetraplegia/paraplegia)

Category	Tetraplegia <i>n</i> =182 %	Paraplegia <i>n</i> =205 %	Total <i>n</i> =387 %
Men/women	88/12	78/22*	83/17
Age at injury (median years) (range)	31.4 (11-77)	25.3** (3-82)	27.9 (3-82)
Cause of injury			
Sports	18	5**	11
Assaults	1	6	4
Transport	47	45	46
Fall	28	36*	32
Others	6	8	7
Unknown	1	1	1
Working accident	19	19	19
Frankel classification			
A	40	53*	47
B	8	4	6
C	8	17*	13
D	41	24**	32
E	2	2	2
Complications during initial rehabilitation	62	55	58
Associated injuries	42	61**	52
Prevalence of chronic medical conditions and/or traumas prior to SCI ^a	23	17	20
History of pre-injury alcohol or substance abuse	5	6	6

^aAll chronic conditions or severe traumas noted in each patient's medical journal, are included.

Differences between tetraplegia and paraplegia: * $p < 0.05$; ** $p < 0.001$.

of the total sample). The predominating secondary medical complications during initial rehabilitation were pressure ulcers (21% of the total sample), urinary tract complications, such as severe infections and calculi (21% of the total sample), and troublesome spasticity (14% of the total sample). Twenty-four patients were included more than one year after injury. The observation period from injury until 31 December 2002 was median 27 years (range 20–39 years). Comparisons of persons injured during the period 1961–75 ($n=198$) vs those injured during the period 1976–82 ($n=189$) were made, but no significant differences were observed. The subjects injured prior to 1976 represented a smaller proportion (i.e. approximately 20%) of the total number of new SCIs in the period 1961–75 than the studied persons injured in the period 1976–82 (i.e. approximately 40% of the total number of new cases injured in the period 1976–82).

Deceased

During the observation period 121 men and 21 women of the 387 patients had died. Table II presents the study population divided by persons who died and persons who survived until 31 December 2002. As expected, age at injury was higher in the deceased compared with the survivors. The deceased were more often injured in fall accidents, but transport or sports accidents were more frequent among the survivors. The group of persons who died comprised a higher proportion of persons with cervical level of injury and the neurological impairment was more commonly classified as Frankel D–E compared with the survivors. Regarding patients with tetraplegia, Frankel D, 62% of these subjects had no bony injury. Analysis within the deceased showed no differences between persons with cervical SCI and those with lower lesions, nor between the patients injured in the first incidence period ($n=76$) vs those injured during the later one ($n=66$).

Causes of death

The predominant underlying causes of death in our sample were respiratory disease ($n=30$, 21%), and in particular pneumonia/fluenza ($n=22$, 16%); ischaemic heart disease ($n=18$, 13%); urogenital diseases ($n=18$, 13%); cancer ($n=17$, 12%); and suicide ($n=9$, 6%). There were no noticeable differences in the causes of death between persons with tetraplegia and those with paraplegia.

Sixty percent of all respiratory deaths were found in individuals classified as Frankel D, most of them (77%) had a tetraplegia. The causes of injury were fall accidents in 50% of the cases. The median age at injury in those who died because of respiratory illness was 61 years (range 17–75 years) and at death 70 years (range 26–94 years). In contrast, subjects who died from suicide were 40 years at injury (range 15–62 years) and at death 46 years (range 22–83 years). However, calculations of the median age at death will change, as well as the frequency of the causes of death, as the survivors will also die in the future. In persons who died because of ischaemic heart disease, 11% had a history of pre-injury CVD. In the deceased classified as Frankel grade A–C, the organ system most

Table II. Characteristics of persons with traumatic spinal cord injury (SCI) included in the study compared by survivors and deceased

Category	Survivors $n=245$ %	Deceased $n=142$ %
Men/women	82/18	85/15
Age at injury (median years) (range)	21.6 (3–58)	52.3* (15–82)
Cause of injury		
Sports	15	4**
Assaults	5	2
Transport	51	37*
Fall	23	49**
Others	6	8
Unknown	1	1
Working accident	18	22
Level of injury		
Tetraplegia	38	63**
Paraplegia	62	37
Frankel classification		
A	52	38*
B	7	4
C	13	13
D	25	43**
E	2	2
Complications during initial rehabilitation	62	55
Associated injuries	51	55
Prevalence of chronic medical conditions and/or traumas prior to SCI ^a	14	31**
History of pre-injury alcohol or substance abuse	3	10*

^aAll chronic conditions or severe traumas noted in each patient's medical journal are included.

Differences between survivors and deceased: * $p<0.05$; ** $p<0.001$.

frequently implicated in death was the urinary tract system. Seventeen of all patients died from neoplasm; i.e. lung cancer ($n=4$), cancer in the urinary tract ($n=5$; 4 bladder cancer, 1 kidney cancer), prostate cancer ($n=3$), abdominal cancer ($n=3$; inclusive, one rectum cancer), cancer in the oral cavity ($n=1$) and cancer of the uterus ($n=1$).

Survival

Fig. 1 illustrates survival in the study population divided into 2 groups, i.e. persons injured during the period 1961–75 and those injured during the period 1976–82. The log-rank test showed no improvement in survival times for those injured after 1 January 1976 ($p=0.67$).

Fig. 2 illustrates age at death or censoring in the study population as well as a control curve of the age at death for the general population.

Standardized mortality ratios

The SMR values are presented in Table III. The ratios were higher for women than for men. The SMR values were also higher for persons injured during the period 1976–82 than for those injured before 1976.

The cause-specific SMRs (Table IV) demonstrate the high prevalence of various causes of death in persons with SCI.

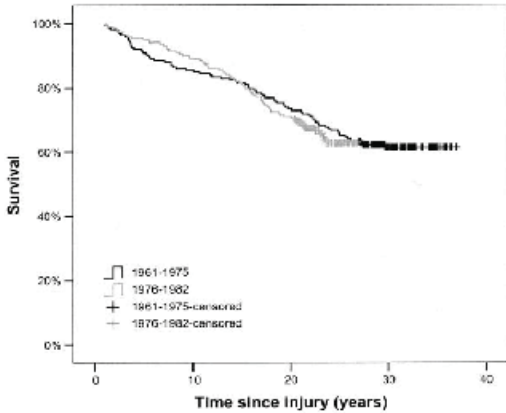


Fig. 1. Survival of traumatic spinal cord injured admitted to Sunnaas Rehabilitation hospital in 1961–1975 and 1976–1982.

Risk indicators for death

The univariate analyses showed that age at injury, marital status at injury, pre-injury occupational classification, place of residence according to 5 regions of Norway, living alone at the time of injury, injury aetiology, neurological level of injury, Frankel classification, pre-injury psychiatric diagnosis, pre-injury CVD, pre-injury respiratory disease, and pre-injury alcohol or substance abuse, were significantly related to the time interval from injury until death or time censored ($p < 0.25$). These factors were included in the multiple Cox regression analysis and the final results are shown in Table V. Significant indicators for death were higher age at injury, cervical level of injury, functionally complete SCI, pre-injury presence of

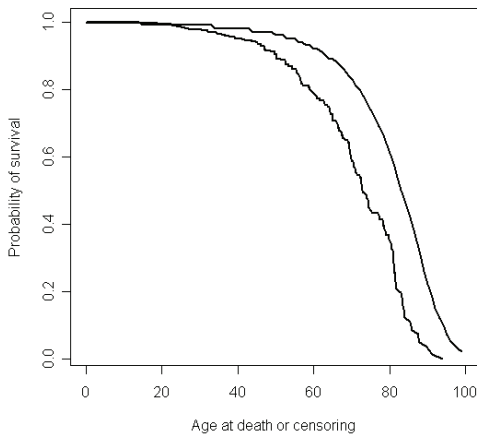


Fig. 2. Illustration of age at death or age at censoring of all persons ($n=387$) with traumatic spinal cord injury admitted to Sunnaas Rehabilitation Hospital 1961–82. The curve above/at right illustrates the age at death in the normal population.

Table III. Standardized mortality ratios (SMRs) for men and women with spinal cord injury (SCI) and incidence period

Category	Men		Women	
	SMR	(95% CI)	SMR	(95% CI)
All SCI ($n = 387$)	1.8	(1.5–2.2)	4.9	(3.0–7.5)
Tetraplegia ($n = 182$)	2.4	(1.9–3.0)	7.6	(3.9–13.3)
Paraplegia ($n = 205$)	1.3	(0.9–1.8)	3.3	(1.5–6.3)
Date of injury between 1961 and 1975	1.5	(1.1–1.9)	4.7	(2.3–8.5)
Date of injury between 1976 and 1982	3.6	(2.7–4.6)	5.5	(2.6–10.2)

CI: Confidence Interval.

CVD, pre-injury presence of psychiatric disease and a history of alcohol or substance abuse before the SCI.

DISCUSSION

The study shows elevated overall SMRs in persons with chronic SCI, especially in women. We also found elevated cause-specific SMRs for urogenital diseases, pneumonia/influenza, suicide, diseases of the digestive system, and urogenital cancer. Furthermore, we showed that age at injury, level and extent of the SCI, and pre-injury medical conditions were predictors of mortality.

Table IV. Standardized mortality ratios (SMRs) for men and women for various causes of death

Cause of death (ICD-9)	SMR (95% CI) ($n =$ actual number of deaths)	
	Men	Women
Septicaemia (038)	6.9 (0.0–39.5) ($n = 1$)	–
Pulmonary cancers (162)	1.0 (0.2–2.9) ($n = 3$)	5.9 (0.0–34.2) ($n = 1$)
Urogenital cancers (188–189)	4.4 (1.4–10.4) ($n = 5$)	–
Neoplasms* (140–239)	0.9 (0.5–1.5) ($n = 14$)	1.4 (0.3–4.1) ($n = 3$)
Ischaemic heart disease (410–414)	0.9 (0.5–1.5) ($n = 18$)	–
Cerebrovascular disease (430–438)	0.8 (0.2–1.8) ($n = 5$)	–
Other vascular disease (440–450)	0.7 (0.0–3.8) ($n = 1$)	5.3 (0.0–30.2) ($n = 1$)
Respiratory disease (460–478) (490–519)	2.7 (0.9–5.9) ($n = 6$)	8.9 (0.9–33.1) ($n = 2$)
Pneumonia and influenza (480–487)	5.6 (3.2–9.1) ($n = 16$)	8.7 (3.1–18.9) ($n = 6$)
Diseases of the digestive organs (520–579)	3.8 (1.5–7.8) ($n = 7$)	–
Diseases of the urogenital system (580–599)	21.9 (12.2–36.3) ($n = 15$)	23.4 (4.4–69.1) ($n = 3$)
Unintentional injuries (E800–E949)	1.6 (0.6–3.5) ($n = 6$)	–
Suicide (E950–E959)	4.7 (1.9–9.7) ($n = 7$)	19.2 (1.8–70.5) ($n = 2$)

*All cancers, including pulmonary and urogenital cancers. CI: confidence interval

Table V. Risk indicators for death

Factors	RR	95% CI	p-value
Age at injury*	1.08	1.06–1.09	<0.001
Paraplegia (ref.)	1.00	–	–
Tetraplegia	1.64	1.12–2.39	0.012
Frankel classes D–E (ref.)	1.00	–	–
Frankel classes A–C	1.84	1.24–2.73	0.002
No cardiovascular disease pre-injury (ref.)	1.00	–	–
Cardiovascular disease pre-injury present	2.80	1.22–6.40	0.015
No psychiatric diagnosis pre-injury (ref.)	1.00	–	–
Psychiatric diagnosis pre-injury present	7.17	2.57–20.01	<0.001
No alcohol or substance abuse pre-injury present (ref.)	1.00	–	–
Alcohol or substance abuse pre-injury present	2.21	1.24–3.93	0.007

*For each year of advancing age at injury, the relative risk (RR) of dying increased by 0.08.

CI: confidence interval.

The dominating underlying causes of death in the study population were pneumonia/influenza, CVD, genitourinary conditions, cancer and suicide. Several other studies have documented a high frequency of respiratory cause of death in chronic SCI; more commonly in persons with complete SCI compared with those with incomplete lesions (1, 10, 14). In our material, the highest percentage of respiratory death was found in individuals classified as Frankel D, although it is notable that their age at injury and at death were fairly high. The fact that respiratory diseases are frequent causes of death in the elderly general population should also be taken into consideration (31). Furthermore, many of these subjects probably had a central cord syndrome, which also may affect respiratory function.

Cigarette smoking is a major risk factor for respiratory disease and CVD, and previous studies have suggested a higher proportion of smokers among persons with SCI compared with the general population (32). Garshick et al. (33) showed that current smokers at study entry had an increase in mortality of 4% per cigarette smoked per day compared with never smokers, in chronic SCI. Our investigation did not include data on cigarette smoking among the studied individuals. Since respiratory disease and CVD were found to be the most common causes of death in our study, information on cigarette smoking would be of value.

It is well known that persons with SCI are exposed to potential risk factors associated with CVD (34), and several studies have found that deaths due to CVD are frequent in this population (1, 2, 4–10, 14). CVD (ICD-9 codes 390–450), predominantly ischaemic heart disease, accounted in total for 23% of the deaths in our investigation. An important finding was the significant association between the presence of pre-injury CVD and premature death in the study population.

Furthermore, the Cox regression also revealed that the presence of pre-injury psychiatric disease as well as pre-injury alcohol or substance abuse were significant predictors for death. Thus, paying attention to co-morbidity and treatable factors must be more emphasized. Garshick et al. (33) recently assessed that diabetes, heart disease, lower levels of pulmonary function, and current or recent smoking were risk factors for death. Krause et al. (22) identified that hospitalization within the 2 years before data collection was associated with mortality, and concluded that greater attention needs to be given to medical secondary conditions that precede mortality.

Hartkopp et al. (6, 35) documented a high suicide rate in individuals with Frankel grade E lesions. Their results showed frequent previous psychiatric diagnoses in individuals who committed suicide. In the current study, 4 persons who committed suicide were classified as Frankel grade A and 5 as Frankel grade D. Psychiatric problems pre-injury were registered in one person only. Information on illness during the period after initial rehabilitation until death was not available. It is well known from studies in the general population that a major proportion of individuals committing suicide suffer from psychiatric illness, above all depression (36, 37). The frequency of suicide in the current study is somewhat lower (6.4% of all deaths) than shown by Hartkopp et al. (6, 35) (9.8%). Yet, the calculated SMRs demonstrate that suicide is a serious problem in the SCI population. Our results emphasize that more attention is needed to detect psychological maladjustment in persons with SCI.

Bombardier et al. (38) concluded that a history of problem drinking may be a risk for poorer rehabilitation progress in patients with SCI. We observed that persons with a history of pre-injury alcohol or substance abuse were at increased risk of premature death. Special attention, including more intensive follow-up of this group, is necessary to detect and prevent illness and thus improve their survival probability. Heightened awareness among rehabilitation staff is needed to reveal alcohol or substance abuse in persons with SCI.

The overall SMRs were higher in women than in men in this study, and the difference seems to be larger than in previous chronic SCI mortality studies (6). In consistency with previous studies, older age at injury as well as level and extent of SCI were associated with mortality.

The calculated SMRs for cancer in the urinary tract system were markedly elevated (in men only), and support earlier observations on increased mortality due to bladder malignancy in persons with SCI (39, 40). The SMRs for septicaemia were not elevated in this study. Several other publications have documented high frequency and/or markedly elevated SMRs for septicaemia in persons with SCI (2, 6, 7, 10, 11, 14). Some of this discrepancy might be a result of different ways of coding causes of death. Septicaemia is usually coded as an immediate (direct) cause of death with either an underlying cause of respiratory infection, urinary infection or pressure ulcer, etc. From the information on the death certificates, we found that septicaemia frequently contributed to death, i.e. septicaemia was coded as the immediate cause of death.

The study was restricted by the selection of patients enrolled. Our data show that a relatively small proportion (approximately 22%) of persons who sustained SCI in Norway were treated at Sunnaas in the 1960s and the early period of the 1970s, in contrast to the number of persons admitted to the hospital after 1974/75 (approximately 45% of all new incidents in Norway). There is no reason to believe that the annual incidence of traumatic SCI was lower during the early period (41). Furthermore, there is lack of information on strategies concerning patient selection for rehabilitation at Sunnaas Rehabilitation Hospital prior to 1973, and also what happened to individuals with SCI who were not admitted to Sunnaas. We assume that a relatively high proportion of persons with higher grade of impairment, and/or older age at injury were sent to local hospitals for treatment and subsequently to local nursing homes. Therefore, a possible bias is that survival is overestimated because the studied sample represents a more selected group concerning the incidences in the 1960s and the early 1970s. If the representativeness had been better in the first incidence period, we believe that our findings concerning risk indicators for death would have shown even more explicit results, at least with regards to age at injury and level and extent of injury.

The results may be biased because of the inclusion of 24 persons who were enrolled in the study more than one year following injury. The survival is probably overestimated because deaths during the first year post-injury were excluded (10, 15, 17).

Concerning the computed cause-specific SMRs, we ended up with some adjusted results. Since 32 cases of death were coded at the Cause of Death Register as deaths due to "Unintentional injuries" (ICD9 codes E800-E949), we decided to recode in those situations where the injury-producing event was listed as the underlying cause of death. Otherwise, the results would indicate high SMR values (i.e. SMR in men: 7.2, CI: 4.7–10.5; SMR in women: 13.8, CI: 4.4–32.4) concerning "Unintentional injuries" (in most cases representing the injury which caused the SCI), which did not seem justified. The SMRs presented (Table IV) are biased, since the actual number of deaths due to "unintentional injuries" was reduced, but the expected number was not altered and thus slightly overestimated in this model. These kinds of deaths (late effects of chronic injuries) are relatively rare in the general population. Some of the SMRs in this study were computed on basis of small numbers of deaths (Table IV), resulting in uncertain values.

In conclusion, the overall SMRs confirm that mortality is high in persons with chronic SCI in Norway, especially in women. In addition to older age at injury and level and completeness of injury, this study shows that pre-injury medical conditions are risk indicators for death. The results highlight the importance of management of co-morbidity in persons with SCI.

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REFERENCES

- Frankel HL, Coll JR, Charlifue SW, Whiteneck GG, Gardner BP, Jamous MA, et al. Long-term survival in spinal cord injury: a fifty-year investigation. *Spinal Cord* 1998; 36: 266–274.
- Whiteneck GG, Charlifue SW, Frankel HL, Fraser MH, Gardner BP, Gerhart KA, et al. Mortality, morbidity and psychosocial outcomes of persons spinal cord injured more than 20 years ago. *Paraplegia* 1992; 30: 617–630.
- Freed MM, Bakst HJ, Barrie DL. Life expectancy, survival rates, and causes of death in civilian patients with spinal cord trauma. *Arch Phys Med Rehabil* 1966; 47: 457–463.
- Geisler WO, Jousse AT, Wynne-Jones M. Survival in traumatic transverse myelitis. *Paraplegia* 1977; 14: 262–275.
- Geisler WO, Jousse AT, Wynne-Jones M, Breithaupt D. Survival in traumatic spinal cord injury. *Paraplegia* 1983; 21: 364–373.
- Hartkopp A, Brønnum-Hansen H, Seidenschnur A-M, Biering-Sørensen F. Survival and cause of death after traumatic spinal cord injury. A long-term epidemiological survey from Denmark. *Spinal Cord* 1997; 35: 78–85.
- DeVivo MJ, Krause JS, Lammertse DP. Recent trends in mortality and causes of death among persons with spinal cord injury. *Arch Phys Med Rehabil* 1999; 80: 1411–1419.
- Le CT, Price M. Survival from spinal cord injury. *J Chronic Dis* 1982; 35: 487–492.
- Samsa GP, Patrick CH, Feussner JR. Long-term survival of veterans with traumatic spinal cord injury. *Arch Neurol* 1993; 50: 909–914.
- DeVivo MJ, Black KJ, Stover SL. Causes of death during the first 12 years after spinal cord injury. *Arch Phys Med Rehabil* 1993; 74: 248–254.
- DeVivo MJ, Kartus PL, Stover SL, Rutt RD, Fine PR. Causes of death for patients with spinal cord injuries. *Arch Intern Med* 1989; 149: 1761–1766.
- Minaire P, Demolin P, Bourret J, Girard R, Berard E, Deidier C, et al. Life expectancy following spinal cord injury: a ten-years survey in the Rhône-Alpes Region France, 1969–1980. *Paraplegia* 1983; 21: 11–15.
- Nakajima A, Honda S, Yoshimura S, Ono Y, Kawamura J, Moriai N. The disease pattern and causes of death of spinal cord injured patients in Japan. *Paraplegia* 1989; 27: 163–171.
- Soden R, Walsh J, Middleton JW, Craven ML, Rutkowski SB, Yeo JD. Causes of death after spinal cord injury. *Spinal Cord* 2000; 38: 604–610.
- Yeo JD, Walsh J, Rutkowski S, Soden R, Craven M, Middleton J. Mortality following spinal cord injury. *Spinal Cord* 1998; 36: 329–336.
- Burke MH, Hicks AF, Robins M, Kessler H. Survival of patients with injuries of the spinal cord. *JAMA* 1960; 172: 121–124.
- DeVivo MJ, Stover SL, Black KJ. Prognostic factors for 12-year survival after spinal cord injury. *Arch Phys Med Rehabil* 1992; 73: 156–162.
- Krause JS, DeVivo MJ, Jackson AB. Health status, community integration, and economic risk factors for mortality after spinal cord injury. *Arch Phys Med Rehabil* 2004; 85: 1764–1773.
- O'Connor PJ. Survival after spinal cord injury in Australia. *Arch Phys Med Rehabil* 2005; 86: 37–47.
- Kiwerski JE. Factors contributing to the increased threat to life following spinal cord injury. *Paraplegia* 1993; 31: 793–799.
- Sneddon DG, Bedbrook G. Survival following traumatic tetraplegia. *Paraplegia* 1982; 20: 201–207.
- Krause JS, Sternberg M, Lottes S, Maides J. Mortality after spinal cord injury: an 11-year prospective study. *Arch Phys Med Rehabil* 1997; 78: 815–821.
- Pedersen AG. A survey of the Cause of Death Registry and the existing rules to establish codes 1996–1997. Report; Official Statistics of Norway; 2000. [in Norwegian].
- Pedersen AG, Strom K, Østevold G, Hoff J, Djume W, Westby G. Causes of death 1991–2000. Report; Official Statistics of Norway; 2003.
- Gjertsen F. The Cause of death registry and research. *Tidsskr Nor*

- Lægeforen 2000; 120: 723–725 [in Norwegian].
26. Gjertsen F. Cause of death registry – an important data source for medical research. *Tidsskr Nor Lægeforen* 2002; 26: 2551–2554, [in Norwegian].
 27. Frankel HL, Hancock DO, Hyslop G, Melzak J, Michaelis LS, Ungar GH, et al. The value of postural reduction in the initial management of closed injuries of the spine with paraplegia and tetraplegia. *Paraplegia* 1969; 7: 179–192.
 28. Krokstad S, Ringdal K, Westin S. Classifying people by social class in population based health surveys: two methods compared. *Norsk Epidemiologi* 2002; 12: 19–25.
 29. Krokstad S, Westin S. Health inequalities by socioeconomic status among men in the Nord-Trøndelag Health Study, Norway. *Scand J Public Health* 2002; 30: 113–124.
 30. Altman DG, ed. *Practical statistics for medical research*, 1st edn. London: Chapman & Hall; 1991.
 31. Statistics Norway. Pneumonia and influenza as cause of death in different age groups. *Official Statistics of Norway*; 2002 [in Norwegian].
 32. Biering-Sørensen F, Biering-Sørensen M. Sleep disturbances in the spinal cord injured: an epidemiological questionnaire investigation, including a normal population. *Spinal Cord* 2001; 39: 505–513.
 33. Garshick E, Kelley A, Cohen SA, Garrison A, Tun CG, Gagnon D, et al. A prospective assessment of mortality in chronic spinal cord injury. *Spinal Cord* 2005; 43: 408–416.
 34. Bauman WA, Kahn NN, Grimm DR, Spungen AM. Risk factors for atherogenesis and cardiovascular autonomic function in persons with spinal cord injury. *Spinal Cord* 1999; 37: 601–616.
 35. Hartkopp A, Brønnum-Hansen H, Seidenschnur A-M, Biering-Sørensen F. Suicide in a spinal cord injured population: its relation to functional status. *Arch Phys Med Rehabil* 1998; 79: 1356–1361.
 36. Kjølsøth I, Ekeberg Ø, Teige B. Suicide among elderly in Norway. *Tidsskr Nor Lægeforen* 2002; 122: 1457–1461 [in Norwegian].
 37. Grøholt B. Risk factors for suicidal behaviour among young people in Norway. *Norsk Epidemiologi* 2002; 12: 207–221 [in Norwegian].
 38. Bombardier CH, Stroud MW, Esselman PC, Rimmele CT. Do preinjury alcohol problems predict poorer rehabilitation progress in persons with spinal cord injury? *Arch Phys Med Rehabil* 2004; 85: 1488–1492.
 39. West DA. Role of chronic catheterization in the development of bladder cancer. *Urology* 1999; 53: 292–297.
 40. Groah SL, Weitzenkamp D, Whiteneck GG, Lezotte DC, Hamman RF. Excess risk of bladder cancer in spinal cord injury: evidence for an association between indwelling catheter use and bladder cancer. *Arch Phys Med Rehabil* 2002; 83: 346–351.
 41. Gjone R, Nordlie L. Incidence of traumatic paraplegia and tetraplegia in Norway: a statistical survey of the years 1974 and 1975. *Paraplegia* 1978; 16: 88–93.

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