

**Medical problems associated with  
spinal cord lesions  
– impact on functioning**

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## ABSTRACT

**Aims:** The overall aim of this thesis was to study the effects of medical problems associated with spinal cord lesions on functioning – with special interest in work participation and sexual functioning. A special aim was to explore bone mineral density and associated factors in persons with meningomyelocele.

**Methods:** The target population comprised persons with traumatic spinal cord injury or meningomyelocele living in the county of Western Götaland in Sweden. The subject characteristics, prevalence of medical problems and other disorders, as well as primary outcomes, were assessed with a structured questionnaire. In the osteoporosis study a physician and a physical therapist examined all subjects and assessed ambulatory status and the neurological level of the lesion. Bone mineral density in the lumbar spine, hip and forearm was measured with dual-energy x-ray absorptiometry. In the workplace intervention study each participant was visited by an ergonomist at the workplace where the working conditions were documented by means of video recordings, questionnaires and the ergonomist's evaluation of the workplace.

**Results:** Work participation rate in Swedish spinal cord lesion population is about two thirds of that in the healthy population (50% against 75%). Among the men with traumatic spinal cord injury, neuropathic pain and the presence of other somatic or mental disorders were associated with work participation, whereas most of these associations were not observed in the women with traumatic spinal cord injury or in the persons with meningomyelocele. The results of the workplace intervention study showed that the working conditions of persons with spinal cord lesion can be improved by ergonomic measures. Satisfaction with sexual life was rather low in all subgroups except in the women with meningomyelocele. Medical problems associated with spinal cord lesion, such as incontinence and neuropathic pain, affected satisfaction with sexual life in persons with traumatic spinal cord injury. In persons with meningomyelocele, none of the studied medical problems was associated with satisfaction with sexual life. The results also indicated that osteopenia and osteoporosis are more common among young adults with meningomyelocele than in the normative population. The effect of medical risk factors of osteoporosis on bone mineral density was modified by ambulatory status in this patient group.

**Conclusions:** Medical problems affect functioning in persons with spinal cord lesion. There are, however, some gender differences, as well as differences between persons with congenital and acquired spinal cord lesion. Osteoporosis is a medical problem, which must be considered when treating and rehabilitating persons with meningomyelocele.

**Key-words:** spinal cord injuries, meningomyelocele, rehabilitation, osteoporosis, bone density, employment, sexuality

## LIST OF PAPERS

This thesis is based on the following papers, which will be referred to in the text by Roman numerals:

- I Valtonen KM, Goksör L-Å, Jonsson O, Mellström D, Alaranta HT, Viikari-Juntura ER. Osteoporosis in Adults With Meningomyelocele: An Unrecognized Problem at Rehabilitation Clinics. *Arch Phys Med Rehabil* 2006;87:376-82.
- II Valtonen K, Karlsson A-K, Alaranta H, Viikari-Juntura E. Work participation among persons with traumatic spinal cord injury and meningomyelocele. *J Rehabil Med* 2006;38:192-200.
- III Valtonen K, Karlsson A-K, Siösteen A, Dahlöf L-G, Viikari-Juntura E. Satisfaction with sexual life among persons with traumatic spinal cord injury and meningomyelocele. *Disability and Rehabilitation (In press)*
- IV Sandsjö L, Valtonen K, Olsson Grundell L, Karlsson A-K, Viikari-Juntura E. Assessment of working conditions and implementation of changes among employees with spinal cord lesion. A case series. *Submitted*.

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## ABBREVIATIONS

ADL	Activities of Daily Living
ASIA	American Spinal Injury Association
BMD	Bone Mineral Density
BMI	Body Mass Index
CI	Confidence Interval
CIC	Clean Intermittent Catheterisation
DBS	Deep Brain Stimulation
DREZ	Dorsal Root Entry Zone
DXA	Dual X-ray Absorptiometry
EDTA	Ethylenediaminetetraacetic Acid
FIM	Functional Independence Measure
ICF	International Classification of Functioning, Disability and Health
MMC	Meningocele
NSAID	Nonsteroidal Anti-Inflammatory Drug
OR	Odds Ratio
PTH	Parathyroid Hormone
RLOC	Rehabilitation Locus of Control
RRT	Relative Rest Time
SCI	Spinal Cord Injury
SCL	Spinal Cord Lesion
SCS	Spinal Cord Stimulation
SD	Standard Deviation
SRFM	Self-Reported Functional Measure
TCS	Tethered Cord Syndrome
TENS	Transcutaneous Electrical Nerve Stimulation
UTI	Urinary Tract Infection
WHO	World Health Organization

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# **1. INTRODUCTION**

## **1.1 Occurrence and consequences of spinal cord lesions (SCL)**

Spinal cord lesions can be divided into traumatic and non-traumatic. The proportion of non-traumatic SCL varies widely, depending mainly on source of information (Catz et al. 2004, Citterio et al. 2004, Exner and Meinecke 1997, McKinley et al. 1999). Based on the most recent studies, the proportion of non-traumatic SCL of all SCL lies between 40% and 65% (Catz et al. 2004, Citterio et al. 2004, McKinley et al. 1999). The clinical picture of SCL is more affected by the neurological level of the lesion than by the etiology of the lesion. SCL are associated with a wide variety of medical problems in multiple organs as well psychosocial problems (Alaranta et al. 2001, Bauman and Spungen 2001, Johnson et al. 1998, McDonald and Sadowsky 2002, McDonnell and McCann 2000b, Nair et al. 2005, Saikkonen et al. 2004, Siösteen et al. 2005, Verhoef et al. 2004). These problems are listed in Table 1 and the medical problems will be dealt with in more detail later in this chapter.

### **1.1.1 Traumatic spinal cord injury (SCI)**

Incidence of traumatic SCI varies widely around the world. According to a recent review by Wyndaele&Wyndaele (2006), the reported incidence of SCI lies somewhere between 10 and 83 per million inhabitants per year. In the Nordic countries the incidence of traumatic SCI is about 11-16 cases per million inhabitants per year (Biering-Sørensen 2002). The data on prevalence are rare. Prevalence rates of 223-755 per million inhabitants have been reported in studies from Australia, Finland, Sweden, and USA (Dahlberg et al. 2005, O'Connor 2005, Wyndaele and Wyndaele 2006).

In the majority of countries traffic accidents are the most common cause of SCI, accounting for 42-47% of all traumatic SCIs (Alaranta et al. 2000, Biering-Sørensen et al. 1990, Jackson et al. 2004). Falls from heights are the next common cause (Alaranta et al. 2000, Biering-Sørensen et al. 1990, Jackson et al. 2004). Sports, especially diving in shallow water, and violence are also fairly common causes of SCI (Alaranta et al. 2000, Biering-Sørensen et al. 1990, Jackson et al. 2004, Valtonen and Alaranta 2001).

Based on a worldwide literature survey, the mean age at injury is 33 years (Wyndaele and Wyndaele 2006). However, mean age at injury has risen during the last years, and in the most recent studies the mean age at injury has been reported to be 38-39 years (Alaranta et al. 2000, Jackson et al. 2004). The majority of the persons with SCI (70-80%) are men, but women have increased their proportion during the last years (Alaranta et al. 2000, Biering-Sørensen et al. 1990, Jackson et al. 2004).



**Table 1.** Medical and non-medical problems associated with spinal cord lesion

**Musculoskeletal system**

Muscle weakness and loss of mobility  
Spasticity  
Osteoporosis and increased risk of fractures  
Joint contractures  
Heterotopic ossification

**Urinary system**

Urinary incontinence  
Retention  
Urinary tract infections  
Bladder and renal calculi

**Gastro-intestinal system**

Constipation  
Faecal incontinence  
Haemorrhoids  
Diarrhoea  
Gastro-oesophageal reflux, gastric and duodenal ulcers

**Skin**

Sensory loss  
Pressure ulcers  
Latex allergy

**Sexual function**

Erectile and ejaculatory dysfunction  
Infertility  
Temporary amenorrhea

**Respiratory system**

Respiratory insufficiency  
Pneumonia and other respiratory infections  
Obstructive sleep apnea  
Pulmonary embolism

**Cardiovascular system**

Hypotension  
Autonomic dysreflexia  
Deep venous thrombosis  
Increased risk for cardiovascular diseases and diabetes

**Concomitant neurological problems**

Traumatic brain injury  
Hydrocephalus and Chiari malformations  
Syringomyelia and tethered cord

**Pain**

Neuropathic pain  
Secondary overuse syndromes  
Abdominal pain

**Psychosocial problems**

Post-traumatic stress disorder, depression and other psychological problems  
Increased drug and alcohol use  
Disturbed family relations  
Financial problems

More than half (51-56%) of all traumatic SCIs are cervical injuries (Biering-Sørensen et al. 1990, Jackson et al. 2004, Knutsdottir 1993), and most studies have reported more incomplete than complete injuries (Dahlberg et al. 2005, Wyndaele and Wyndaele 2006). However, in a large study (n=30 532) from the US, when the ASIA grade (Maynard et al. 1997) and level of injury were combined, the percentages were as follows: tetraplegia incomplete 30.6%, paraplegia complete 26.1%, tetraplegia complete 23.4%, paraplegia incomplete 19.2%, and normal 0.7% (Jackson et al. 2004).

Previous studies indicate that a concomitant traumatic brain injury is seen in 24-59% of patients with traumatic SCI (Sommer and Witkiewicz 2004). The cognitive and behavioral sequelae of the traumatic brain injury create a special challenge for SCI rehabilitation.

### **1.1.2 Non-traumatic spinal cord lesions**

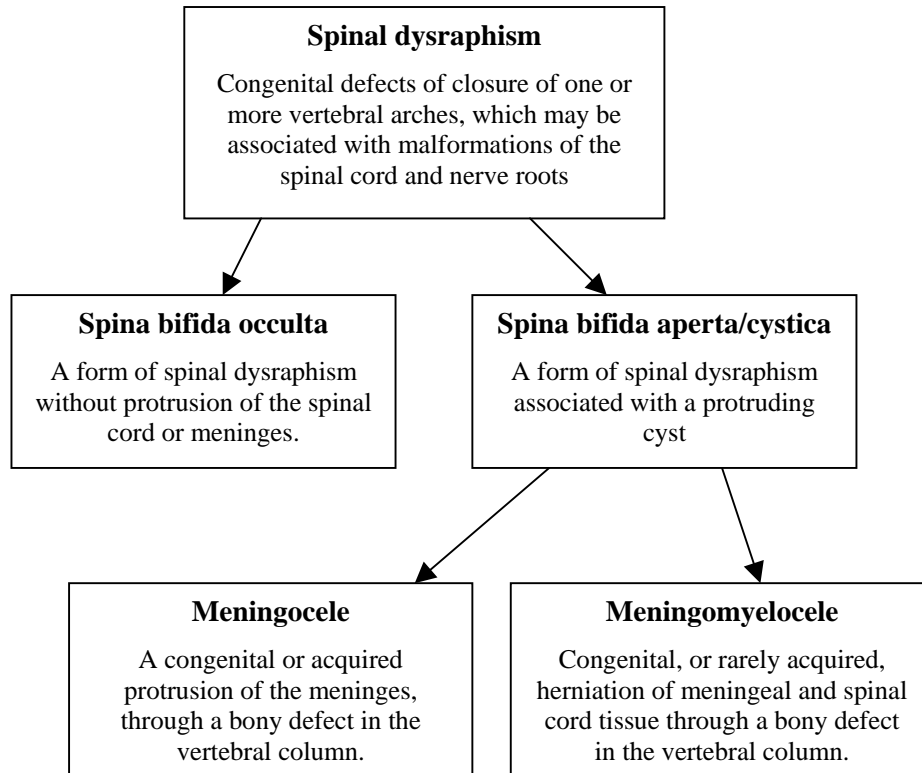
There are few data concerning the epidemiology and functional outcome of persons with non-traumatic SCL. This is probably due to large etiological heterogeneity of non-traumatic SCL. In a recent study from Israel (Catz et al. 2004), the mean age at the injury among persons with non-traumatic SCL was reported to be 47.8 years (range 0-82 years), which is clearly higher than that for persons with traumatic SCI. The male/female ratio was 1.2:1. The etiology of the lesion was spinal stenosis in 24.1%, disc protrusion in 14.6%, multiple sclerosis in 21.8%, tumor (e.g. meningioma, ependymoma, astrocytoma, schwannoma, and hemangioma) in 20.3%, myelitis in 6.5%, other infection in 4.7%, C1-C2 instability (mostly associated with rheumatoid arthritis) in 2.7%, vascular malformation in 2.2%, spinal cord ischemia after non-spinal surgery in 1.6%, and spina bifida in 0.7%. The cervical spinal cord was affected in 32.1% of the cases, thoracic spinal cord in 45.2%, and the lumbar in 22.8%. Less than 3% of the injured had complete lesion.

#### ***Meningomyelocele (MMC)***

Meningomyelocele, or spina bifida cystica, is a congenital malformation of the neural tube in which the spinal cord and nerve roots herniate through a defect in the vertebral arches and dura (Figure 1). The condition results in varying sensory and motor deficits below the affected neurological level, which most often (ca 70% of cases) is located in the lumbosacral region (Hunt and Oakeshott 2003, McDonnell and McCann 2000b, Rintoul et al. 2002). In addition to muscle weakness and sensory loss, associated problems include impaired bladder and bowel control and hydrocephalus, the latter being seen in more than 80% of the cases (Cate et al. 2002, Tomlinson and Sugarman 1995). The functional ability and ambulatory status of these patients can vary considerably, depending mainly on the neurological level of the lesion. In spite of active rehabilitation, only about 30-50% of the persons with meningocele become community

walkers and 30-40% are wheelchair users (Mirzai et al. 1998). Moreover, some studies have shown deterioration of the neurological level and walking ability already in the adolescence (Bartonek et al. 1999).

**Figure 1.** Terminology concerning MMC



Internationally the incidence of meningocele ranges from 0.2 to 5 per 1000 live births (Botto et al. 1999, McDonnell and McCann 2000b, The National Board of Health and Welfare 2003). In Sweden the incidence has varied between 0.2 and 0.4 per 1000 live births during the last few years (The National Board of Health and Welfare 2003). MMC is somewhat more common in the men than in the women (male to female ratio 1.3:1) (Hunt and Oakeshott 2003). Previous studies have shown a risk of MMC as high as 4% in the offspring of MMC patients. The risk is similar whether the affected parent is male or female (de Vylder et al. 2004). The overall incidence of meningocele has declined significantly in the last two decades mainly because of an increase in termination of pregnancies as a result of prenatal screening, but also because of a wider use of periconception folate (Birnbacher et al. 2002, Persad et al. 2002). On the other hand, the survival rate has increased significantly. Before 1960 only 10% of

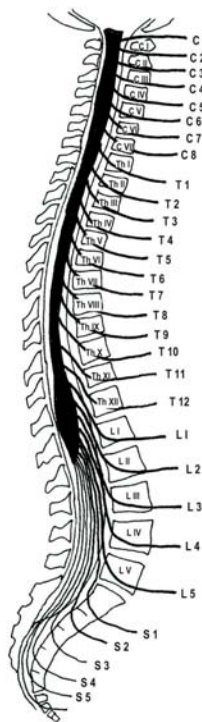
infants born with meningocele survived; the majority died due to infection or hydrocephalus. With major development in the technique of shunt operations and subsequent management of shunt function, it is estimated that at least 50-70% of the children born with spina bifida today will survive into adulthood (McDonnell and McCann 2000b).

## 1.2 Medical problems associated with spinal cord lesions

### 1.2.1 Impaired bladder function

Neurogenic bladder is one of the most important medical problems in SCL. Depending on the neurological level of lesion there are two types of problems. Firstly, a lesion at the sacral micturition center (S2-4 level (see Figure 2)) usually leads to decreased or absent detrusor contractility (detrusor areflexia), and flaccid bladder. On the contrary, a lesion located above the sacral level may lead to either involuntary, reflexive emptying of the full bladder, or it may also lead to detrusor hyperreflexia resulting in urge incontinence (Benevento and Sipski 2002, Burns et al. 2001).

**Figure 2.** Vertebral column, spinal cord and nerve roots (Figure by Johanna Paulin)



The main goals in bladder management are to diminish incontinence and prevent complications, such as urinary tract infections, renal and bladder calculi and renal insufficiency (hydronephrosis, vesicoureteral reflux) (Benevento and Sipski 2002, Burns et al. 2001). Urodynamic studies should be performed to all patients with SCL after the spinal shock period to determine bladder function. Regular follow-up is also recommended (Burns et al. 2001).

Urinary incontinence is a problem often associated with neurogenic bladder (Dahlberg et al. 2004). Approximately one fourth of persons with SCL report uncontrolled urinary leakage on a weekly or daily basis (Levi et al. 1995, Verhoef et al. 2004). In previous studies persons with SCL have reported incontinence being one of the most bothersome complications following SCL, and urinary incontinence has also been shown to be associated with lower self-reported quality of life (Hicken et al. 2001, Lin et al. 1997, Lundqvist et al. 1991, Westgren and Levi 1998). Urinary tract infections (UTIs) are common among persons with SCL (Levi et al. 1995, Saikkonen et al. 2004, Weld and Dmochowski 2000). Adequate bladder emptying and sufficient drinking of fluids are the most important means to prevent recurrent UTIs (Giannantoni et al. 1998, Weld and Dmochowski 2000). Recurrent UTIs, use of indwelling catheters, and immobilisation-related hypercalciuria increase the risk for renal and bladder calculi in persons with SCL (Burns et al. 2001).

There are several methods for bladder emptying, i.e. clean intermittent catheterisations (CIC), subrapubic catheters, indwelling catheters, and condom sheath catheters. Of these CIC is probably the most recommendable method since it has been shown to prevent vesicoureteral reflux and UTIs in persons with SCL (Benevento and Sipski 2002, Giannantoni et al. 1998, Weld and Dmochowski 2000). The choice of bladder emptying method, however, should be made on an individual basis. For persons with poor hand function, other emptying methods than CIC might be better by providing better chances to higher independence in bladder emptying (Benevento and Sipski 2002).

Bladder hyperreflexia can, and should be suppressed with anticholinergic agents to avoid high pressures during urine storage and uninhibited detrusor contractions (Benevento and Sipski 2002, Burns et al. 2001, Giannantoni et al. 1998). In men another possibility is to use  $\alpha$ -blockers to reduce outflow resistance by blocking  $\alpha$ -receptors at bladder neck and internal sphincter (Benevento and Sipski 2002, Burns et al. 2001). Botulinum A toxin injections have also been used to treat dyssynergia and detrusor hyperreflexia (Burns et al. 2001).

If the drugs fail to work, surgical treatment can be considered. Bladder augmentation, in which part of the ileum is resected to form a reservoir, is one of the treatment methods in detrusor hyperreflexia. Urinary diversion surgery, in

which an easier outlet is built from the augmented bladder to the surface, may facilitate independent CIC also for persons with higher level of injury (Benevento and Sipski 2002, Burns et al. 2001). There are two main types of urinary diversions, Bricker conduit and Kock reservoir (a continent cutaneous ileal reservoir) (Pannek and Senge 1998). In persons with detrusor areflexia or detrusor-sphincter dyssynergia transurethral sphincterotomy or placement of a urethral stent can be used to reduce outlet obstruction (Biering-Sørensen and Hartkopp 1995, Burns et al. 2001). One of the most modern techniques to treat neurogenic bladder is electric stimulation of the sacral anterior nerve roots (Benevento and Sipski 2002, Burns et al. 2001).

### **1.2.2 Impaired bowel function**

Persons with SCL rank bowel dysfunction as one of their major life-limiting problems (Glickman and Kamm 1996, Levi et al. 1995). Constipation and faecal incontinence are the most often reported symptoms of neurogenic bowel dysfunction. Previous studies have shown that approximately one third of the persons with SCL suffers from constipation, and somewhat less from faecal incontinence (Glickmann and Kamm 1996, Han et al. 1998, Kannisto and Rintala 1995, Verhoef et al. 2004). Other commonly reported problems include haemorrhoids, abdominal pain, abdominal distention, diarrhea, gastro-oesophageal reflux, nausea, and autonomic dysreflexia of gastrointestinal origin (Glickmann and Kamm 1996, Han et al. 1998, Stone et al. 1990, Verhoef et al. 2004).

Neurogenic bowel dysfunction can be divided into two different types depending on the neurological level of lesion (Benevento and Sipski 2002, Lynch et al. 2001, Stiens et al. 1997). Injury above the sacral level (upper motor neuron lesion) results in loss of conscious sphincter control, and inability to fully increase intra-abdominal pressure. Colonic activity is often increased, which may lead to overactive segmental peristalsis, underactive propulsive peristalsis, and a spastic external anal sphincter constriction. As a result, colon transit time is prolonged, and there is increased risk of constipation and faecal distention of the colon (Kannisto and Rintala 1995). Injury at the sacral spinal cord, roots, or peripheral nerve innervation of the colon (lower motor neuron lesion) often causes lack of tone in the external anal sphincter, which increases the risk of faecal incontinence. Furthermore, spinal cord –mediated reflex peristalsis of the colon may be absent, which often leads to constipation.

The main goals in bowel care are to avoid excessive build-up of faeces, faecal incontinence and other complications by means of effective faecal evacuation in the least amount of time. Regularity of bowel care is important (Lynch et al. 2001, Stiens et al. 1997). Defecation should occur every 1 to 3 days, in lower motor neuron lesions even more frequently (Stiens et al. 1997). Mucosal

stimulation either digitally or with a suppository, enema, or mini-enema is needed to initiate reflex defecation (Lynch et al. 2001, Stiens et al. 1997). Especially in lower motor neuron lesions anorectal reflexes are often insufficient to result in defecation and the stool has to be removed manually (Lynch et al. 2001, Stiens et al. 1997). Adequate fluid intake promotes transit by softening the stool, and adequate fiber intake assists colonic transit by allowing the stool to form sufficient bulk and a plastic consistency (Lynch et al. 2001, Stiens et al. 1997). In addition, to modulate stool consistency, motility and defecation, different types of medications, such as bulk-forming agents, stool softeners, laxatives, or prokinetic agents, are often required (Lynch et al. 2001, Stiens et al. 1997). If conservative methods fail to work, a few surgical procedures may be considered (Lynch et al. 2001, Stiens et al. 1997). A colostomy or ileostomy may be an alternative for persons with severe constipation or extremely long bowel care time (Benevento and Sipski 2002, Lynch et al. 2001, Stiens et al. 1997). A sacral anterior nerve root stimulator used in treatment of neurogenic bladder can also be used to initiate defecation (Stiens et al. 1997).

### **1.2.3 Pain**

Pain is a major problem for persons with SCL. Pain interferes with daily functioning and quality of life (Norrbrink Budh et al. 2003, Putzke et al. 2002, Siddall et al. 2003). Previous studies indicate that two-thirds of persons with SCL report pain, and nearly one-third of those with pain rate their pain as severe (Burchiel and Hsu 2001, Siddall et al. 1997). Predictors of pain following SCL are unclear (Finnerup and Jensen 2004). Results concerning the effect of the neurological level of injury and etiology of injury are inconsistent and lack compelling evidence (Burchiel and Hsu 2001).

Pain following SCL can be divided into two major categories: nociceptive pain and neuropathic pain. Nociceptive pain can be further divided into musculoskeletal and visceral pain types, and neuropathic pain can be divided into above-level, at-level, and below-level types, where level refers to the level of the spinal cord lesion. Musculoskeletal pain is usually described as dull, aching, movement-related, and eased by rest. Visceral pain is usually described as dull or cramping abdominal uncomfortable and painful sensations, which may be associated with nausea and autonomic reactions. Dysreflexic headache is included in this category. The qualities of neuropathic pain can be sharp, shooting, burning, aching, pricking, tingling, or electrical. Dysaesthesias (i.e. unpleasant abnormal sensations), and paraesthesias (i.e. nonpainful abnormal sensations) are frequently seen in neuropathic pain (Burchiel and Hsu 2001, Finnerup and Jensen 2004). The taxonomy of SCL related pain is presented in Table 2.

**Table 2.** Taxonomy of SCL pain according to Siddall et al (Siddall et al. 2000).

Broad type (Tier 1)	Broad system (Tier 2)	Specific structures and pathology (Tier 3)
Nociceptive	Musculoskeletal	Bone, joint, muscle trauma or inflammation Mechanical instability Muscle spasm Secondary overuse syndromes
	Visceral	Renal calculus, bowel dysfunction, sphincter dysfunction etc. Dysreflexic headache
Neuropathic	Above-level	Compressive mononeuropathies Complex regional pain syndromes
	At-level	Nerve root compression (including cauda equina) Syringomyelia Spinal cord trauma/ischemia Dual level cord and root trauma
	Below-level	Spinal cord trauma/ischemia

Musculoskeletal pain is usually responsive to paracetamol, nonsteroidal anti-inflammatory drugs and opioids. However, oral pharmacologic therapy for severe SCL pain is relatively ineffective (Burchiel and Hsu 2001). Although antidepressants have been shown to be effective in peripheral neuropathic chronic pain in non-SCL patients, there is a lack of studies showing their effectiveness in SCL pain (Burchiel and Hsu 2001, Finnerup and Jensen 2004, Finnerup et al. 2001). Results concerning effect of anticonvulsants, such as carbamazepin and gabapentin, in SCL pain, are inconsistent (Burchiel and Hsu 2001, Finnerup and Jensen 2004, Finnerup et al. 2001, Levendoglu et al. 2005). There is some evidence that opioids, as well as baclofen, a GABA<sub>B</sub>-receptor agonist, may have some effect in neuropathic pain (Finnerup and Jensen 2004, Finnerup et al. 2001). Intrathecal drug therapy with combinations of agents such as morphine, clonidine, and baclofen is a potential choice of treatment in SCL pain (Finnerup and Jensen 2004, Finnerup et al. 2001).

The data on the use of transcutaneous electrical stimulation (TENS) in SCL patients is rare, but it seems to be effective in some patients with muscular pain or at-level neuropathic pain, but not in patients with below-level pain (Burchiel and Hsu 2001, Finnerup et al. 2001). Spinal cord stimulation (SCS), and deep brain stimulation (DBS) have also been used for the pain relief in persons with SCL, but they seem to lack long-term effectiveness (Burchiel and Hsu 2001, Finnerup et al. 2001). In some cases surgical treatment, such as cordotomy, cordectomy, or dorsal root entry zone (DREZ) operations, can be considered (Burchiel and Hsu 2001, Finnerup et al. 2001).



#### 1.2.4 Spasticity

Spasticity is most commonly defined as abnormal increase in tone (muscle hypertonia) and velocity-dependent increased resistance to muscle stretch (Adams and Hicks 2005, Burchiel and Hsu 2001). Furthermore, spasticity is usually accompanied by hyperreflexia and variable degrees of muscle weakness (Adams and Hicks 2005, Sköld et al. 1999). However, in the most recent literature, a modified definition of spasticity has been introduced. According to Decq (2003), spasticity is defined as a symptom of upper motor neuron syndrome characterised by exaggeration of the stretch reflex secondary to hyperexcitability of spinal reflexes. Furthermore, there are three subdefinitions of spasticity: 1) intrinsic tonic spasticity: exaggeration of the tonic component of the stretch reflex (manifesting as increased tone), 2) intrinsic phasic spasticity: exaggeration of the phasic component of the stretch reflex (manifesting as tendon hyperreflexia and clonus), and 3) extrinsic spasticity: exaggeration of extrinsic flexion or extension spinal reflexes.

Spasticity, which becomes evident only after the resolution of spinal shock, is a common phenomenon in SCL. Previous studies have shown that 65-78% of persons with SCL have symptoms of spasticity (Adams and Hicks 2005). Studying prevalence of spasticity is difficult because of large interindividual, as well as intraindividual, variations. Previous studies have shown that there is a large discrepancy between self-reported spasticity and spasticity assessed by an investigator (Priebe et al. 1996, Sköld et al. 1999). Therefore, both methods should be considered when assessing the impact of spasticity on a persons daily living.

Persons with spasticity often perceive spasticity as problematic in daily functioning (Adams and Hicks 2005, Sköld et al. 1999). Extension spasticity often interferes with transfers, and when elicited suddenly, may force a person in a wheelchair to fall over, whereas flexion spasticity interferes with sleep (Little et al. 1989). Furthermore, the literature has shown an association between spasticity and other medical problems, such as contractures, decubitus ulcers, pain, stress, infections, and poor perineal hygiene (Burchiel and Hsu 2001, Sköld et al. 1999). On the other hand, spasticity may in some cases be beneficial for an individual, e.g. by increasing stability in sitting and standing or by facilitating the performance of some ADL and transfers (Adams and Hicks 2005, Sköld et al. 1999). In a Swedish study 11% of the persons perceived their spasticity as beneficial (Sköld et al. 1999).

The pathophysiologic basis of spasticity is incompletely understood. The final effect, however, is a strong facilitation of transmission in the monosynaptic reflex pathway from Ia sensory fibers to  $\alpha$  motoneurons (Burchiel and Hsu 2001, Satkunam 2003). Therefore, therapeutic treatment aims at disruption of the

myostatic reflex, which in turn decreases the output of  $\alpha$  motoneurons. Although it is generally agreed that methods of physical therapy, such as muscle stretching, weight-bearing and positioning, are an essential part in the management of spasticity, there is few data on its effectiveness (Adams and Hicks 2005). The most effective pharmacological agents for reducing spasticity include baclofen and diazepam, which act predominantly within the central nervous system, and dantrolene, which acts directly on skeletal muscle (Adams and Hicks 2005, Burchiel and Hsu 2001). Newer agents, such as tizanidine and botulinum toxin, have also been tried with success (Burchiel and Hsu 2001).

Although many surgical procedures to treat spasticity are available, only a few are currently used in persons with SCL. Intrathecal delivery of baclofen is probably the most common of them. Intrathecally administered baclofen is more effective and has less negative systemic side effects than orally administered agent (Burchiel and Hsu 2001). Spinal cord stimulation (SCS) is a potentially beneficial method to control spasticity, which, however, seems to lack long-term effectiveness (Burchiel and Hsu 2001). Surgical procedures, such as myelotomy, rhizotomies, and orthopaedic procedures, i.e. tendon lengthening, release or transfer, are rarely used today (Chambers 1997, Satkunam 2003).

### **1.2.5 Sexual dysfunction**

To what extent SCL affects sexual function varies depending on gender, and the neurological level and degree of injury. There are also some differences between congenital and acquired spinal cord injuries. In persons with congenital SCL, such as MMC, there has never been a normal physiological development of sexual function and therefore neither congenital reflexes nor experience derived organisation of communications between nerve cells exist (de Vylder et al. 2004). Furthermore, persons with congenital SCL have no pre-injury sexual life, which they could use as a reference. These people learn to cope with those functional impairments they have already from birth, but sexual maturation may create new challenges at teen and young adult age (Börjeson and Lagergren 1990, Rintoul et al. 2002, Sawyer and Roberts 1999). Sexual dysfunction is dealt with here from the medical and physiological point of view, and from the point of view of functioning later (1.4).

#### ***Men***

Erection can occur either reflexively through a parasympathetic center located in the spinal cord segments S2-4, or psychogenically via a sympathetic center located at T11-L2 level. Men with complete lesions above the level of T11 often experience reflex erections but lack capacity for psychogenic erection. Men with a complete lower motor neuron lesion below L2 level show no reflex erection but may experience psychogenic erection. In incomplete injuries the capacity for psychogenic erection depends on the degree of preserved neurological function

at T11-L2 level (Benevento and Sipski 2002, Biering-Sørensen and Sønksen 2001, Monga et al. 1999 ).

There are several treatment options for erectile dysfunction in men with SCL. Several studies have shown that use of sildenafil, a phosphodiesterase inhibitor, is safe and effective in the treatment of erectile dysfunction in men with SCL (Benevento and Sipski 2002, Biering-Sørensen and Sønksen 2001, Monga et al. 1999). Intracavernous injections of vasoactive agents, such as papaverine, phentolamine, and prostaglandin E1, have been shown to be effective in treatment of erectile dysfunction in men with SCL (Benevento and Sipski 2002, Biering-Sørensen and Sønksen 2001, Monga et al. 1999). Prostaglandin E1 can also be administered intraurethrally, even though it is not as effective as when administered intracavernously (Benevento and Sipski 2002, Biering-Sørensen and Sønksen 2001, Monga et al. 1999). Vacuum erection device uses negative pressure to promote inflow of blood into the penis. The erection is then maintained by placing a constriction band at the base of the penis (Benevento and Sipski 2002, Biering-Sørensen and Sønksen 2001, Monga et al. 1999). The use of various penile prostheses has declined because of new treatment alternatives and complications, such as skin breakdown and infections (Benevento and Sipski 2002, Biering-Sørensen and Sønksen 2001, Monga et al. 1999).

Both the sympathetic center located at T11-L2 level, and the parasympathetic center located at the S2-4 level, as well as the somatic center, located in S2-4 with fibres in the pudendal nerve, are needed for successful ejaculation. Therefore the ejaculation ability is nearly always affected by SCL (Benevento and Sipski 2002, Biering-Sørensen and Sønksen 2001, Monga et al. 1999 ). Based on the results of a literature survey in 1992, the median for ability to ejaculate during sexual stimulation or masturbation was as low as 15% (range from 0% to 55%) (Biering-Sørensen and Sønksen 2001). In a Swedish study among men with MMC, only 2 of 9 participants were able to achieve unassisted ejaculation (Hultling et al. 2000).

Augmentative techniques have been developed to produce an ejaculate in men with SCL. Vibratory stimulation involves the application of a hand-held vibrator to the glans penis and frenulum of the penis to trigger an ejaculatory reflex. With electroejaculation, ejaculation is induced using electrical stimulation via a rectal probe. Vibratory stimulation is most successful in men with an upper motor neuron lesion above T11 level. Penile vibratory stimulation is usually preferred because it is less invasive and the quality of semen obtained is better than with electroejaculation. By using penile vibratory stimulation or electroejaculation, semen can be harvested in 80-90% of cases (Biering-Sørensen and Sønksen 2001, DeForge et al. 2005). Furthermore, if semen is not obtained otherwise or if

the semen quality is very poor, spermatozoa can be obtained via microsurgical sperm aspiration (Dahlberg et al. 1995).

Even though nearly all men with SCL are able to produce an ejaculate naturally through masturbation or sexual contact, or with use of augmentative techniques, the ability to procreate is still strongly impaired due to abnormal semen characteristics (Biering-Sørensen and Sønksen 2001, Hultling et al. 2000). The reason for poor semen quality in men with SCL is not fully understood. Several reasons, such as recurrent urinary tract infections, testicular hyperthermia, prostatic fluid stasis, abnormal testicular histology, changes in the hypothalamic-pituitary testicular axis, sperm antibodies, spermatozoa contact with urine through retrograde ejaculation, testicular denervation, changes in seminal fluid, and long-term use of various medications, have been suggested to explain the reduced semen quality and motility in men with SCL (Benevento and Sipski 2002, Biering-Sørensen and Sønksen 2001, Burns et al. 2001, McDonald and Sadowsky 2002). There is also evidence that men who use intermittent catheterization for bladder emptying show better semen quality than men who use other methods for bladder emptying (Biering-Sørensen and Sønksen 2001).

Even though erectile dysfunction and diminished fertility are common in men with SCL, current treatment options make it possible to obtain semen from nearly all men with SCL (Dahlberg et al. 1995). In a study among men with MMC, spermatogenesis was seen in 6 of 9 men (Hultling et al. 2000). After obtaining semen, partner pregnancy can be achieved by means of different kinds of insemination techniques with success rates for achieving a pregnancy of up to 51% (DeForge et al. 2005).

### ***Women***

Neurological control of lubrication and erection of the clitoris is both central and peripheral. Psychogenically induced vaginal lubrication and swelling is impaired if the injury is located above S2-4 level. Women with complete upper motor neuron lesions have the ability for reflex but not psychogenic lubrication (Benevento and Sipski 2002, Burns et al. 2001). Laboratory studies have shown that women with preservation of sensory function in dermatomes T11-L2 show a greater likelihood of achieving psychogenic lubrication (Benevento and Sipski 2002). It has been shown in small case-control studies, that even in females with supposedly complete SCL, sexual arousal can be increased with manual genital stimulation, although requiring a higher level of concentration than in able-bodied controls (Sipski et al. 1996). It has also been demonstrated that with manual and audiovisual stimulation combined, more than half of SCL women experience orgasms that can not be differentiated from able-bodied controls (Sipski et al. 2001).

In women an acquired SCL usually results in temporary amenorrhea for 6 to 12 months after the lesion. It seems that after the return of ovulation cycles SCL has no impact on female fertility. This statement, however, has poor scientific basis (Benevento and Sipski 2002, DeForge et al. 2005, Hovatta and Dahlberg 1996).

Women with MMC often show precocious puberty, the beginning of puberty typically occurring 1.5-2 years earlier than normal. This is due to the high incidence of hypothalamic and pituitary dysfunction probably secondary to hydrocephalus, which leads to an early release of gonadotropins (de Vylder et al. 2004). Women with MMC are thought to have normal fertility, even though there are no studies with comparison to general population (de Vylder et al. 2004).

### **1.2.6 Pressure ulcers**

Pressure ulcers are areas of soft tissue breakdown that result from sustained mechanical loading of the skin and underlying tissues (Bouten et al. 2003). A pressure ulcer develops when the blood supply to the skin and tissues is reduced or stopped. Based on several studies, the prevalence of pressure ulcers among persons with SCL varies between 12% and 34% (Chen et al. 2005, Krause et al. 2001, National Spinal Cord Injury Statistical Center 2005, New et al. 2004, Saikkonen et al. 2004). In a cohort study carried out by Hunt and Oakeshott (2003) in persons with MMC, 30 persons out of 54 had had pressure ulcers. In persons with traumatic SCI the life-time likelihood has been reported to be as high as 85% (Byrne and Salzberg 1996, New et al. 2004). There is evidence that decubitus ulcers affect both physical and social functioning (Langemo et al. 2000, Sapountzi-Krepia et al. 1998). Studies in persons with SCL suggest that longer time since injury, higher degree of neurological impairments, lower independence in daily activities, smoking, being underweight, and spasticity increase the risk of pressure ulcers (Byrne and Salzberg 1996, Garbe et al. 2000, Krause et al. 2001).

Prevention of decubitus ulcers is essential, since treatment is difficult, as well as time and money consuming (Brem and Lyder 2004). The cornerstone in pressure ulcer prevention and treatment is to limit pressure and the time over which pressure is applied. In addition to regular repositioning, i.e. weight shifting while sitting in a wheelchair and turning in bed, specialised support surfaces for wheelchairs and bedding to decrease pressure should be used (Bansal et al. 2005, Brem and Lyder 2004). Additionally, every patient at risk for developing an ulcer, should daily examine the skin around the trochanteric, sacral, ischial, and heel areas (Brem and Lyder 2004).

The main aspects in wound care include removal of nonviable tissue (debridement) and effective wound-bed preparation while protecting the skin

adjacent to the wound (Bansal et al. 2005, Brem and Lyder 2004). Different kinds of topical agents and dressings are available for this purpose (Brem and Lyder 2004). Deep ulcers can be treated surgically with debridement and repair by a flap (Sørensen et al. 2004). Good nutritional status is essential for healing of pressure ulcers. Dietary supplements, enteral feedings or even parenteral feedings, may be required (Brem and Lyder 2004). Quitting smoking, prevention of joint contractures, and effective treatment of spasticity are some of the other important aspects in the prevention and treatment of pressure ulcers (Brem and Lyder 2004).

### **1.2.7 Osteoporosis**

Osteoporosis is a disease characterised by reduction of total bone mass and microarchitectural deterioration of bone tissue. These changes are associated with an increased rate of fractures. Risk factors for osteoporosis include age, female sex, smoking, parental history of hip fracture, and physical inactivity (Kanis 2002). It can be assumed that patients with SCL are a potential risk group for developing osteoporosis at a younger age, because of impaired walking ability and subsequent low physical loading of the lower limbs. Furthermore, due to a neurogenic bladder dysfunction these patients are more prone to develop renal failure, which is a known risk factor for osteoporosis (Kanis 2002). Urinary diversion surgery, in which part of the ileum is resected to form a reservoir, is a common treatment method of neurogenic bladder, which may cause acidosis and osteoporosis (Abes et al. 2003). Epilepsy is also fairly common in patients with MMC and medication for epilepsy can increase the risk for osteoporosis (Farhat et al. 2002).

Spinal cord lesion leads to increase in bone turnover (Roberts et al. 2006). The results of bone turnover markers suggest that an imbalance between elevated bone resorption and normal (or slightly elevated) bone formation after SCL leads to diminished BMD (Roberts et al. 2006). In addition to bone loss, SCL may also alter bone structure and microarchitecture (Jiang et al. 2006). Trabecular bone is more affected than cortical bone in persons with SCL (Jiang et al. 2006). The underlying cause of lowered BMD in persons with SCL is not fully understood. Disuse probably plays a major role, but also factors such as poor nutritional status, disordered vasoregulation, hypercortisolism (either therapeutic or stress-related), alterations in gonadal function, and other endocrine disorders may be involved (Jiang et al. 2006). It has been suggested that a new steady state level between bone resorption and formation is re-established about 2 years after SCL, but this remains controversial (Jiang et al. 2006).

Previous studies have shown that several factors influence BMD in persons with SCL. The neurological level of lesion has an impact on BMD (Jiang et al. 2006). Persons with tetraplegia have lower BMD than persons with paraplegia, and

persons with complete lesions have lower BMD than persons with incomplete lesions. Older age, female gender, longer time since injury, and longer duration of acute post-traumatic immobilisation seem to increase the risk of bone loss in persons with SCL (Jiang et al. 2006). The results concerning the effect of spasticity on BMD have been somewhat inconsistent (Jiang et al. 2006).

A high incidence of lower extremity fractures has been reported in numerous clinical case series in persons with SCL. Especially supracondylar fractures of the distal femur are common (Jiang et al. 2006, Lloyd et al. 2006). On the other hand, the absence of published reports of vertebral compression fractures suggests that they are rare in persons with SCL (Jiang et al. 2006). In fact, several studies have reported normal, or even higher than normal, BMD values in the lumbar spine (Jiang et al. 2006, Kannisto et al. 1998). The phenomenon has been named dissociated hip and spine demineralisation (Jiang et al. 2006). In general, bone demineralisation after SCL is limited to sublesional areas, i.e. pelvis and lower extremities in persons with paraplegia, and upper extremities in addition to pelvis and lower extremities in persons with tetraplegia, whereas there is no demineralisation in supralesional areas (Dauty et al. 2000).

Although several studies have shown that persons with MMC are prone to pathologic fractures, studies on BMD in MMC are almost nonexistent (Quan et al. 1998, Rosenstein et al. 1987). In nondisabled children BMD increases with age until it peaks in early adulthood. This has been shown to be true also in children with MMC (Quan et al. 1998, Rosenstein et al. 1987). However, it has been reported that BMD in children and young adults with MMC falls 1 to 2 standard deviations (SDs) below that of the normative population (Koch et al. 1992, Quan et al. 1998). Previous data also suggest that both neurologic level and ambulatory status affect BMD in children with MMC (Rosenstein et al. 1987). Comparisons between MMC children with bladder augmentation and never-augmented MMC children have shown no significant difference in BMD (Koch et al. 1992, Mingin et al. 2002).

Healing of osteoporotic fractures may take time. Considering the effects of prolonged immobilisation on independence in daily activities and quality of life, there should be no disagreement that all efforts are necessary to prevent these fractures. Furthermore, one osteoporotic fracture may lead to a vicious circle of immobilisation, decreased bone density, and repeated fractures.

Due to impairments in ambulation and functioning, subjects with spinal cord injury may spend more time inside and become even more easily institutionalised. This may result in reduced exposure to sunshine, which in turn may lead to reduced production of vitamin D in the body and disturbance of calcium metabolism. Suppressed vitamin D levels may also be caused by

suppressed parathyroid hormone (PTH) concentration, which is commonly seen in persons with SCL (Jiang et al. 2006). Treatment with both calcium and vitamin D has been shown to be cost effective in able-bodied adults (Boonen et al. 2004). Although supplementation of calcium and vitamin D cannot prevent osteoporosis after SCL, it may contribute to calcium homeostasis and should therefore be added to the medication of subjects with SCL and osteoporosis. On the other hand, constipation is a frequent problem in these patients and supplementary calcium may worsen it. This must be taken into consideration and laxatives should be added into treatment when necessary.

Previous studies have shown promising results of bisphosphonates in the treatment of osteoporosis in patients with traumatic SCI or cerebral palsy (Henderson et al. 2002, Sniger and Garshick 2002, Zehnder et al. 2004). Presumably, similar effects could be seen in patients with MMC. Calcitonin has been shown to be more effective in the prevention of vertebral fractures than in the prevention of hip fractures in osteoporosis (Mehta et al. 2003). Therefore it may not be the first treatment option in patients with SCL where dissociated osteoporosis is commonly seen. On the other hand, in SCL patients, calcitonin has been shown to counteract the early increase in bone resorption. In addition, calcitonin and etidronate have a rapid and combined effect on the treatment of hypercalcemia after SCL. A recombinant human parathyroid hormone teriparatide has been shown clinically to improve BMD in postmenopausal women and men (Quattrocchi and Kourlas 2004). There are no studies concerning the effects of teriparatide in persons with functional impairments. In animal studies, however, promising results in the prevention of immobilization-related bone loss have been shown (Sakai et al. 1999). Hydrochlorothiazide has been shown to increase BMD in patients with hypercalciuria (Legroux-Gerot et al. 2004). Because hypercalciuria is commonly seen persons with SCL, hydrochlorothiazide could be a potential treatment option for osteoporosis in this patient group (Jiang et al. 2006, Quan et al. 2003). In one study, use of hydrochlorothiazide for one year did not affect BMD, but it reduced urinary calcium excretion in nonambulatory children with MMC (Quan et al. 2003). The effect of standing on bone density is not clear (Caulton et al. 2004, Kunkel et al. 1993). Previous studies have shown promising results of regular functional electric stimulation-assisted training but this is often nearly impossible to carry out in daily life (Belanger et al. 2000).

### **1.2.8 Hydrocephalus and Chiari malformations**

More than 80% of persons with MMC will have associated hydrocephalus (Marlin 2004, Rintoul et al. 2002). The aetiology of the hydrocephalus in persons with MMC is not fully understood. Arnold-Chiari malformation, however, plays a major role in the pathogenesis of the hydrocephalus. Chiari malformations are congenital malformations involving the brainstem,



cerebellum, upper spinal cord, and surrounding bony structures. Based on radiological findings, Chiari malformation is seen in 66-92% of persons with MMC (Bono et al. 1993, Just et al. 1990, Rand-Hendriksen and Christensen 1998). The Chiari Type II malformation, also called Arnold-Chiari malformation, is the most common of these malformations and seen only in persons with MMC. Its typical features include small posterior fossa, hindbrain herniation into the upper cervical spinal canal, dysgenesis of the corpus callosum, and hydrocephalus. The hydrocephalus in these patients has been thought to result from aqueductal stenosis or blockage of the outlets of the fourth ventricle caused by the small posterior fossa and tightness of the intradural contents of the upper cervical canal. Venous abnormalities resulting from small posterior fossa have also been suggested as a mechanism for the hydrocephalus (Marlin 2004). The Chiari type II malformation also affects cerebellar functioning, and may lead to impairments in motor skills, hand function, and oculomotor function (Mataró et al. 2001). Symptomatic Chiari malformation II accounts for more deaths before the age of 2 years than any other cause in patients with MMC (Stevenson 2004).

Hydrocephalus in persons with MMC has been shown to be associated with mild cognitive impairment, poor academic skills in arithmetics, disturbances in visual and tactile perception, fine motor speed, and perceptual motor-integration, and mildly limited ability to reason and judge cause and effect adequately (Mataró et al. 2001). Neurological level of the lesion, shunt status, and the presence of shunt complications has been shown to affect IQ (Mataró et al. 2001). The presence of hydrocephalus also affects independence in daily activities. Verhoef et al (2004) found out in the study in 181 persons with spina bifida that almost all persons without hydrocephalus were independent for all domains of the FIM except for sphincter control, whereas persons with hydrocephalus were much more likely to be dependent on the assistance of others.

The initial step in the treatment of new-borns with MMC should be closure of the defect in the back. Early closure (within the first 72 hours of life) has been shown to decrease the risk of ventriculitis. Shunting may be performed at the same time. Ventriculo-peritoneal shunt placement is the first choice and atrial shunt another alternative, when ventriculo-peritoneal shunt is not possible. There is some evidence, that surgical repair of MMC before birth may decrease the need of shunting (Rintoul et al. 2002).

Shunt complications, such as shunt obstruction, shunt infection, and overdrainage, are common. In a study carried out in persons with MMC aged 14-31 years, the average number of shunt revisions needed per person was 3.6 (range 0-28) (Tomlinson and Sugarman 1995). In the majority of cases, shunt malfunction is easily diagnosed because of classical signs and symptoms of increased intracranial pressure, such as headache, vomiting, and lethargy.

Compensation can, however, occur with development of syringomyelia (1.2.9), i.e. obstruction of the outlets of the fourth ventricle causes leaking of CSF from the fourth ventricle into the central canal, leading to a widening of the canal (Marlin 2004, Milhorat 2000). Because of this compensation mechanism, the shunt malfunction may be more difficult to diagnose. For example, decreased performance at school, epilepsy, hyperactivity, and emotional disturbances may be symptoms of shunt malfunction. Asymptomatic shunt malfunction is also common. The patients with shunts should, therefore, be under regular neurological follow-up with annual ophthalmological evaluation (Marlin 2004).

### **1.2.9 Syringomyelia and tethered spinal cord**

The term syringomyelia refers to longitudinally orientated cerebrospinal fluid-filled cavities in the spinal cord, which are lined by dense, gliogenous tissue. Syringomyelia can accompany both congenital and acquired spinal cord injuries. The development of syringomyelia can give rise to clinical symptoms 2 months to 40 years after the injury (Carroll and Brackenridge 2005). In recent studies incidence of post-traumatic syringomyelia has varied from 0.3% to 3.2% (Carroll and Brackenridge 2005). The radiological and autopsy incidence, however, appears to be higher than the clinical incidence, reaching up to 22% (Carroll and Brackenridge 2005, Vannemreddy et al. 2002). Although syringomyelia can be detected radiologically in 23-53% of persons with MMC, symptomatic syringomyelia is considered to be rare (less than 10%) (Caldarelli et al. 1998, Erkan et al. 2000). In MMC, hydrocephalus and Chiari malformation are considered to have an important role in pathogenesis of syrinx formation. Complete lesion, older age at injury, dislocated spinal fracture, and spinal instrumentation without decompression increase the risk for earlier development of post-traumatic syringomyelia (Vannemreddy et al. 2002). The clinical symptoms of syringomyelia include pain, increasing loss of motor or sensory function, increasing spasticity, autonomic dysreflexia, hyperhidrosis, altered bladder and bowel function, increasing respiratory difficulties, and Horner's syndrome (Lee et al. 2001). The diagnosis is made with MRI (Lee et al. 2001).

Syringomyelia may be accompanied by tethering of the spinal cord, i.e. attachment of spinal cord to surrounding tissues (Lee et al. 2001). Essentially all persons with surgically repaired meningomyelocele will have a tethered spinal cord, and tethering of the spinal cord is commonly seen also in patients with post-traumatic syringomyelia (Hudgins and Gilreath 2004, Lee et al. 2001). The term tethered spinal cord syndrome (TCS) is used when neurological deterioration is related to the tethered spinal cord, and not to the syringomyelia (Hudgins and Gilreath 2004, Lee et al. 2001, Schoenmakers et al. 2003).

The treatment of symptomatic syringomyelia consists primarily of shunting of the syrinx (Lee et al. 2001). Sometimes the size of the syrinx is decreased by

untethering alone (Lee et al. 2001). Despite shunting of the cyst to the pleural, peritoneal, or subarachnoid space, clinical improvement has not been long-lasting, and revision shunt surgery is rather frequent (Lee et al. 2001).

### **1.2.10 Heterotopic ossification**

Heterotopic ossification is defined as the presence of lamellar bone around the joints at locations where bone normally does not exist (Vanden Bossche and Vanderstraeten 2005). The incidence in persons with SCL ranges from 10 to 53%. The incidence seems to be somewhat lower in persons with non-traumatic SCL when compared with traumatic SCI (Bouchard and D'Astous 1991, van Kuijk et al. 2002,). The clinical spectrum of heterotopic ossification ranges from an incidental finding on radiographs to severe limitation of the range of motion and even complete ankylosis of peripheral joints (van Kuijk et al. 2002). Heterotopic ossification occurs most commonly at the hip, but other body segments including the knee, elbow, shoulder, hand and spine may also be involved (Vanden Bossche and Vanderstraeten 2005, van Kuijk et al. 2002). Although heterotopic ossification may develop even several years after SCL, it is usually diagnosed 1 to 6 months post-injury (van Kuijk et al. 2002). The typical clinical findings are a decreased joint range of motion and a strong inflammatory reaction with peri-articular swelling, warmth, low-grade fever, peri-articular erythema, pain, and increased spasticity (van Kuijk et al. 2002).

The precise aetiology of heterotopic ossification is still unknown. Humoral, neural, and local factors probably all play a role in the formation of ectopic bone (Vanden Bossche and Vanderstraeten 2005, van Kuijk et al. 2002). Local microtrauma, caused by mechanical stress, may induce ossification either indirectly through an inflammatory response or directly by releasing osteoblast-stimulating factors (van Kuijk et al. 2002). Several risk factors have been associated with heterotopic ossification (Vanden Bossche and Vanderstraeten 2005, van Kuijk et al. 2002). Heterotopic ossification is more commonly seen in persons with complete injuries when compared with incomplete injuries (van Kuijk et al. 2002). Other clinical factors associated with heterotopic ossification are pressure ulcers, infections, renal stones, deep venous thrombosis, and severe spasticity (van Kuijk et al. 2002). However, apart from the completeness of SCL and the possible role of (micro)trauma, reports of possible risk factors, and their presumed causal relationship with heterotopic ossification, are inconclusive (Vanden Bossche and Vanderstraeten 2005, van Kuijk et al. 2002).

Heterotopic ossification is primarily diagnosed based on clinical signs and likelihood (Vanden Bossche and Vanderstraeten 2005, van Kuijk et al. 2002). Determination of serum alkaline phosphatase, conventional radiography, and ultrasonography are the most often used methods in the diagnosis and follow-up (Banovac et al. 2004, Singh et al. 2003, Vanden Bossche and Vanderstraeten

2005, van Kuijk et al. 2002). Once heterotopic ossification has been diagnosed, patients can be treated with bisphosphonates. It is essential to start treatment as soon as possible and continue it for sufficiently long period of time, i.e. at least 6 months (Vanden Bossche and Vanderstraeten 2005). NSAIDs (mainly indomethasin) and irradiation therapy can also be used in the prevention of heterotopic ossification in persons with SCL (van Kuijk et al. 2002). Currently, surgery is the only treatment that is capable of removing already formed bone. In monotherapy, however, recurrence rate is extremely high, and therefore, surgical resection must always be combined with NSAID or postoperative radiation therapy (van Kuijk et al. 2002).

### **1.2.11 Autonomic dysreflexia**

Autonomic dysreflexia is an acute syndrome associated with SCL, in which a noxious stimulus below the level of lesion produces an afferent impulse that generates a generalised sympathetic response resulting in vasoconstriction below the neurologic level of the lesion (Karlsson et al. 1998). The condition is fairly common in persons with a level of lesion above the fifth to sixth thoracic segment (Karlsson 1999). On rare occasions, it is also seen in patients with a lesion below T6, but in this situation the reaction is usually somewhat milder (Karlsson 1999). The reported occurrence varies widely, and estimates of lifetime occurrence have ranged from 19% to 70% (Blackmer 2003). Autonomic dysreflexia is more common in persons with complete lesions when compared with those with incomplete lesions (Blackmer 2003). Furthermore, the reaction seems to be milder in those with incomplete lesions (Blackmer 2003).

Most common symptoms of autonomic dysreflexia include pounding headache, flushing and sweating above the level of the lesion, shivering, tachycardia (or reflex bradycardia), nasal congestion, malaise and nausea (Blackmer 2003, Bycroft et al. 2005, Karlsson 1999). The main physical finding is elevation of blood pressure. Systolic blood pressure as high as 250-300 mmHg, and diastolic blood pressure as high as 200-220 mmHg during an episode of autonomic dysreflexia have been reported (Blackmer 2003, Karlsson 1999).

Bladder and bowel distension seem to be the most common precipitants of autonomic dysreflexia, but basically any noxious stimulus occurring below the level of injury can trigger an episode of autonomic dysreflexia (Blackmer 2003, Bycroft et al. 2005, Karlsson 1999). Perhaps the most important causes to consider are urinary tract infection, pressure sore, ingrown toenail, skeletal fracture, joint dislocation, ejaculation, sexual intercourse, and labour (Blackmer 2003, Karlsson 1999). An episode of autonomic dysreflexia can also be triggered by iatrogenic causes, e.g. urodynamic evaluation, penile vibratory stimulation, electroejaculation, and functional electrical stimulation of lower extremities (Karlsson 1999).

Early recognition of the condition is essential so that treatment can be initiated immediately (Blackmer 2003). Failure to properly manage autonomic dysreflexia can result in extreme hypertension, which may lead to cerebral or subarachnoid hemorrhage, seizures, atrial fibrillation, neurogenic pulmonary edema, retinal hemorrhage, coma or death (Karlsson 1999). The most important thing is to look for a triggering factor, and eliminate it, if possible (Blackmer 2003, Bycroft et al. 2005, Karlsson 1999). In many cases, draining the bladder alleviates the symptoms (Blackmer 2003). Medical treatment is needed, if the elevated blood pressure does not start to decline after one minute or if the cause can not be determined. Glyceryl trinitrate (e.g. Nitromex), nifedipine, and ramipril have been used for this purpose (Blackmer 2003, Karlsson 1999). Prevention of autonomic dysreflexia is the best approach and therefore proper bladder, bowel, and skin care is essential in persons with SCL. In recurrent episodes of autonomic dysreflexia, prophylactic treatment with alpha-blocking agents may be needed. During labour and delivery, the risk of autonomic dysreflexia in women with lesion at or above T6 is very high (85-90%). The use of epidural or spinal anesthesia can prevent autonomic dysreflexia and should therefore be used routinely in at-risk patients (Blackmer 2003).

### 1.2.12 Other medical problems

Respiratory function may be impaired in SCL due to paresis of respiratory muscles. The degree of respiratory impairment increases with progressively higher levels of injury. The diaphragm may be paralysed in lesions at C4 level and above, and mechanical ventilation or a phrenic stimulator may be needed. **Respiratory complications**, such as atelectasis, pneumonia, and respiratory failure, occur in 50-67% of persons with SCL (Winslow and Rozovsky 2003). The frequency of respiratory complications parallels the degree of respiratory impairment. There is also evidence that the prevalence of **obstructive sleep apneas** is higher in persons with cervical spinal cord lesion than in non-injured population (Klefbeck et al. 1998).

Because of loss of mobility, persons with SCL have an increased risk to develop **deep venous thrombosis (DVT) and pulmonary embolism**. The incidence of DVT as high as 100% has been reported during the acute phase after traumatic SCI, whereas the incidence is clearly lower in chronic SCI (Kim et al. 1994, Myllynen et al. 1985). Advances in thromboprophylaxis, i.e. the use of low-molecular-weight heparin and compression stockings, have significantly reduced the prevalence of DVT and pulmonary embolism after SCL (Winslow and Rozovsky 2003).

**Joint contractures** are common in persons with SCL because of motor deficits and spasticity. Contractures affect functional capacity and predispose to

spasticity, decubitus ulcers, sleep disturbances, and pain (Dalyan et al. 1998). Contractures may be prevented by appropriate muscle stretching (Harvey and Herbert 2002).

Recent studies have shown that persons with SCI are more likely to have insulin resistance, elevated low-density lipoprotein cholesterol, and reduced high-density lipoprotein cholesterol, associated with **increased prevalence of diabetes mellitus and cardiovascular diseases** when compared with the able-bodied population (Bauman and Spungen 2001, Karlsson et al. 1995).

**Latex allergy** is a well-known complication of repeated exposure to natural rubber latex secondary to, for example, surgical procedures and use of indwelling catheter. Therefore, it can be assumed that persons with SCL are a potential risk group for developing latex allergy. In fact, there are several reports showing that latex allergy is commonly seen in persons with meningomyelocele (Gulbahar et al. 2004, Mazagri and Ventureyra 1999, Obojski et al. 2002). However, reports concerning prevalence of latex allergy in persons with traumatic spinal cord injury are somewhat inconsistent (Mertes et al. 2001, Vogel et al. 1995). It has been shown that primary latex prophylaxis during surgery can prevent latex sensitization in young spina bifida patients (Cremer et al. 1998).

Post-traumatic stress reaction, depression, and other **psychological problems** are common among persons with SCI (Levi et al. 1995, Nielsen 2003, Saikkonen et al. 2004). Older age at injury, a pre-injury history of depression, a history of substance abuse, and permanent neurological impairment increase the risk of depressive symptoms (Dryden et al. 2005, Saikkonen et al. 2004). There is evidence that antidepressant medication and psychotherapy are useful means to treat depression following SCL (Kemp et al. 2004).

### **1.3 Work participation**

#### ***SCI***

Among persons with traumatic SCI the overall employment rates have varied between 9% and 80% during the last decades (Table 3) (Biering-Sørensen et al. 1992, Siösteen et al. 1990b, Tasiemski et al. 2000). This wide variation between different studies is mainly due to different study designs and inclusion criteria. The studies on work participation in traumatic SCI carried out during the last 20 years with sample size larger than 100 are presented in Table 3.

**Table 3.** Employment status and factors affecting employability in persons with traumatic spinal cord injury

Study	N	Employment rate % (Studying %)	Factors affecting employability
Murphy et al. 2003 (Australia)	459	47% (10%)	Education, time since injury, FIM, internal RLOC, chance RLOC, work attitude
Anderson and Vogel 2002 (USA)	195	51% (6%)	Education, gender, level of injury, community integration, FIM, independent driving, living independently, higher income, life satisfaction, marital status, pressure ulcer, severe UTIs, spasticity, respiratory complications, hospitalisations
Hess et al. 2000 (USA)	Year 1: 1523 Year 2: 1077 Year 3: 746	Year 1: 21% Year 2: 21% Year 3: 23%	Year 1: Education, motor index score, ethnicity, age at injury, marital status Year 2: Education, motor index score, marital status, ethnicity Year 3: Education, motor index score, ethnicity
Tomassen et al. 2000 (The Netherlands)	234	37%	Age, gender, Barthel Index, education, pre-injury work intensity
Conroy and McKenna 1999 (Australia)	167	44%	Age at injury, pre-injury occupation, lack of independent transport, perceived discrimination, perceived lack of skills, financial disincentives, perceived environmental barriers
Krause et al. 1999 (USA)	3756	22% (12%)	Time since injury, ethnicity, etiology of injury, age at injury, neurological level of injury, employment status at injury, education
Krause et al. 1998 (USA)	Midwestern: 597 Southeastern: 435	Midwestern: 50% Southeastern: 26%	Midwestern: Age, age at injury, years since injury, education Southeastern: Age, age at injury, years since injury, neurological level, education, race, gender
Krause 1997 (USA)	235	1985: 49% 1994: 55%	.
Lovell et al. 1997 (UK)	118	26%	Pension level better or the same as preinjury military service pay
Murphy et al. 1997 (Australia)	219	37%	Age, gender, impairment type, education, compensation entitlement
Athanassou et al. 1996 (Australia)	139	31%	.
Krause and Anson 1996 (USA)	362	25%	Age, age at injury, gender, race, level and completeness of injury, education
Kruse et al. 1996 (USA)	391	30%	Education, ability to drive, injury severity, race
Levi et al. 1996 (Sweden)	326	46% (7%)	.
Castle 1994 (UK)	114	31% (21%)	Age, level of injury, education
van Asbeck et al. 1994 (The Netherlands)	117	32% (5%)	.
Krause 1992 (USA)	286	48%	Age, age at injury, education
Nakajima and Honda 1988 (Japan)	926	28%	.
DeVivo et al. 1987 (USA)	154	19% (7%)	Age, race, education, level of injury, motivation to return to work, intelligence (IQ), requirements of the person's last preinjury job, having children

RLOC = Rehabilitation Locus of control. Internal RLOC measures the extent to which one believes that internal factors are responsible for rehabilitation outcome. Chance RLOC measures the extent to which one believes that rehabilitation outcome is a matter of fate, luck or chance.

Previous studies have shown that higher chronological age and higher age at injury onset are associated with lower employment rates whereas longer time since injury predicts better outcome. In a large study (n=2980) from the US the employment rate was only 14% one year post-injury, whereas it was nearly 40% when more than 20 years had passed since injury (Krause et al. 1999). The results concerning the association between the neurological level of the injury and work participation are somewhat inconsistent (Krause et al. 1999). The only modifiable factor that has been widely studied is education and in the majority of studies more years of education has predicted better work participation (Anderson and Vogel 2002, Krause et al. 1999, Murphy et al. 2003, Tomassen et al. 2000). Few studies have dealt with the effects of medical problems related to SCL or the effects of other mental or somatic disorders on work participation. In a study carried out in subjects with pediatric-onset SCL, there was a greater number of injury-related medical complications among the unemployed group when compared with those who were employed (Anderson and Vogel 2002).

Studies on working conditions and ergonomical interventions at the workplaces of persons with SCL are almost non-existent (Dowler et al. 1998, Inge et al. 1998, Yasuda et al. 2002). Dowler et al. (1998) examined over 1000 cases from the Job Accommodation Network caseload that involved workers with SCL. Typical job functions to be accommodated for workers with paraplegia were most often related to the gross motor skills, such as accessibility, manual material handling, reaching, and driving a vehicle, whereas persons with tetraplegia more often reported problems with job functions involving fine motor skills, such as gripping small objects, pressing buttons and using a keyboard. Nearly half of the accommodation suggestions included information on a product or modification to existing equipment and nearly 20% included changes to the work station. No studies concerning bullying at workplace of persons with traumatic SCI were found.

### ***MMC***

There are few data concerning work participation among persons with meningomyelocele. The overall employment rates have varied from 19% to 53% (Table 4). In a British cohort study, 26% of persons with meningomyelocele were in open employment (Hunt et al. 1999). A somewhat more optimistic employment rate was reported from Ireland, where 34% of a clinical spina bifida population, with or without shunt, were in open employment (McDonnell and McCann 2000a).

Only a few studies have addressed the factors affecting employability in persons with meningomyelocele. The results concerning the role of functional impairments have been somewhat inconsistent. In one study no association was found between physical capacity or ambulatory status and work participation, whereas in another study the chances of being employed tended to decrease with



**Table 4.** Summary of selected studies on the employment rates and factors affecting employability in MMC

Study	N	Mean age (range), Years	Disability	Employment rate %	Studying % <sup>*</sup>	Factors affecting employability
McDonnell and McCann 2000a (Northern Ireland, UK)	95 <sup>*</sup>	25.6 (16-39)	63 % wheelchair users 100% with shunt	36.1%	16.4%	.
Hunt et al. 1999 (England, UK)	57	30.0 (26.5-32.8)	30% community ambulators 70% IQ>80 84% with shunt	26.3%	.	.
Loomis et al. 1997 (USA)	32	27.3 (18-46)	22% thoracic, 56% lumbar, 22% sacral 72% IQ>80 69% with shunt	53.1%	.	Family environment
Tew et al. 1990 (Wales, UK)	98	No ages reported	47 % wheelchair users 95% IQ>74 (<60-65 excluded)	33%	.	Intelligence (IQ), highest academic qualification obtained, toileting, behaviour, overall Putilbec score **, living district (S.Wales vs. Avon)
Hunt 1990 (England, UK)	69	17.7 (16.1-20.2)	51% wheelchair users 68% IQ>80 87% with shunt	7.2%	49.3%	.
Lonton et al. 1984 (England, UK)	157	22.4 (18-26)	59% wheelchair users 57% with shunt 9% normal continence	15.3%	.	.
Lonton et al. 1983 (England, UK)	115	(18-25)**	57% wheelchair users 55% with shunt	23%	.	Sensory level of lesion, shunt
Smith 1983 (Scotland, UK)	126	24.5 (16-73)	29% normal unlimited mobility 27% with shunt	34%	.	.

<sup>\*</sup> Employment rate known only for 61 subjects

<sup>\*\*</sup> The Putilbec scale is a method to evaluate physical, behavioural and sensory functioning

<sup>\*\*\*</sup> Age interval of all 508 myelomeningocele patients at Lodge Moor Hospital of which only 115 took part in the study

increasing disability (Lonton et al. 1983, Tew et al. 1990). In one study, in which patients with the lowest intelligence had been excluded, higher intelligence, better educational level, and higher independence in toileting predicted participation in work (Tew et al. 1990). There is also evidence that family environment and behavioural functioning affect participation in work in persons with meningomyelocele (Loomis et al. 1997, Tew et al. 1990).

According to studies made in the UK wages of persons with MMC fell well below the national average (Lonton et al. 1983, Lonton et al. 1984, Smith 1983, Tew et al. 1990). This might be partly due to the fact that most of those employed (44-49%) had skilled, non-manual jobs such as typist, clerical worker, receptionist and telephonist. According to one study in subjects with meningomyelocele employers showed unfavourable attitudes towards the disabled in 9-10% of cases and 2% of the responders reported having been encountered with unfavorable attitudes by their workmates (Lonton et al. 1983, Lonton et al. 1984). No studies on workplace accommodations were found.

#### **1.4. Sexual functioning**

##### ***SCI***

Traumatic SCI can affect sexual life in many ways, not only because of physiological impairment but also because of psychological distress (Kreuter et al. 1996, Sipski and Alexander 2001, Westgren et al. 1997). Previous studies have shown that sexual desire, sexual activity, and sexual satisfaction decrease after an injury (Fisher et al. 2002, Kreuter et al. 1996). On the other hand, it has been shown that the nature of sexuality and intimacy changes after an injury (Sipski and Alexander 2001). Kissing, hugging, and caressing have been reported as preferred sexual activities rather than sexual intercourse (Sipski and Alexander 2001). The psychological functioning of the relationship has been reported to be more important than the physical aspects of sexual life (Sipski and Alexander 2001). Previous studies also indicate that living with a stable partner increases sexual satisfaction (Black et al. 1998, Nosek et al. 1996).

Sexual satisfaction has been shown to decrease with age in persons with spinal cord injuries, whereas no such effect has been seen in age- and gender-matched controls (Black et al. 1998, Kreuter et al. 1996, Siösteen et al. 1990a). There is also evidence that those with younger age at injury adapt their sexual activity after spinal cord injury more easily than those with older age at injury (Westgren et al. 1997). Although sexual dysfunction caused by spinal cord injury differs between men and women, no gender difference in sexual adjustment after spinal cord injury was detected in a controlled study by Kreuter et al (1996). Somewhat surprisingly, in the majority of the studies no association has been found

between the degree of neurological impairment and sexual adjustment (Kreuter et al. 1996, Siösteen et al. 1990a, Westgren et al. 1997).

Spinal cord injury is often accompanied by different kinds of medical problems, such as urinary and faecal incontinence, neuropathic pain and decubitus ulcers, which all may have their consequences on sexual activity and sexual satisfaction (Levi et al. 1995, Sadowsky et al. 2002). In fact, previous studies have shown that urinary and faecal incontinence, as well as spasticity are among the most often reported concerns of sexually active women with traumatic SCI (Jackson and Wadley 1999, Westgren et al. 1997, White et al. 1993). Although there are studies showing that neuropathic pain and decubitus ulcers affect both physical and social functioning, I am not aware of studies on their effects on sexual satisfaction (Haythornwhite and Benrud-Larsson 2000, Langemo et al. 2000).

### ***MMC***

Fairly little is known about sexual life in persons with meningomyelocele. Tünte reported in 1971 that among 26 persons with meningomyelocele there were 14 marriages, which had resulted in 24 live-born children. Information about the neurological level of the injury was somewhat limited but it can be assumed that those persons were not severely handicapped since they were born and had survived when the techniques to operate the defect and treat the hydrocephalus were not known (Tünte 1971). Several studies have shown that persons with meningomyelocele express the same desire for intimate relationship as non-disabled persons (deVylder et al. 2004, Sawyer and Roberts 1999, Vroege et al. 1998). However, they are also concerned about factors, such as uncertainty of future health and urinary incontinence, affecting their intimate relationships and sexual life (Sawyer and Roberts 1999). To what extent the presence of concomitant hydrocephalus affects sexual life is poorly understood, but based on the results of one study it seems that persons with hydrocephalus experience more problems with their sexual life than those without (Verhoef et al. 2005). However, it has been shown that persons with even more severe cognitive disability have a need for close relationship and sexual expression (Löfgren-Mårtenson 2004).

## **1.5 Rationale for this thesis**

As described above, SCL is usually associated with several medical problems originating from different organ systems. These problems may affect functioning not only by taking extra time in daily routines but also because of psychological distress they may cause. Even though it can be assumed that these problems affect functioning, there are few data on these associations. Furthermore, those few studies exploring this matter are nearly all carried out in persons with traumatic SCI, whereas studies in persons with SCL of non-traumatic origin are nearly non-existent. Accordingly, there is a need for knowledge on impact of these medical problems on functioning, e.g. work participation and sexual functioning, in persons with SCL, and especially in persons with congenital SCL.

## **2. AIMS OF THE STUDY**

The overall purpose of this thesis was to study the effects of medical problems associated with spinal cord lesions on functioning – with special interest in participation.

The study-specific aims were:

- To assess the prevalence of osteoporosis and osteopenia in adults with meningomyelocele (Paper I).
- To explore whether BMD and osteoporosis are associated with neurologic level, ambulatory status, and medical problems associated with meningomyelocele (Paper I).
- To find out whether subject characteristics, injury-related factors, and medical problems related to injury affect participation in work among persons with traumatic SCI or meningomyelocele (Paper II).
- To characterise the employment held by these subjects, as well as to assess satisfaction with work and life situation (Paper II).
- To investigate satisfaction with sexual life and the self-assessed sufficiency of sexual counselling in persons with traumatic spinal cord injury and meningomyelocele (Paper III).
- To find out if individual factors, marital status, and physiological factors affect satisfaction with sexual life in persons with SCL (Paper III).
- To evaluate working conditions in persons with SCL (Paper IV).
- To design and implement measures to reduce physical load at the workplace of persons with different types of SCL (Paper IV).
- To study the feasibility of myofeedback training in persons with SCL (Paper IV).

### 3. SUBJECTS AND METHODS

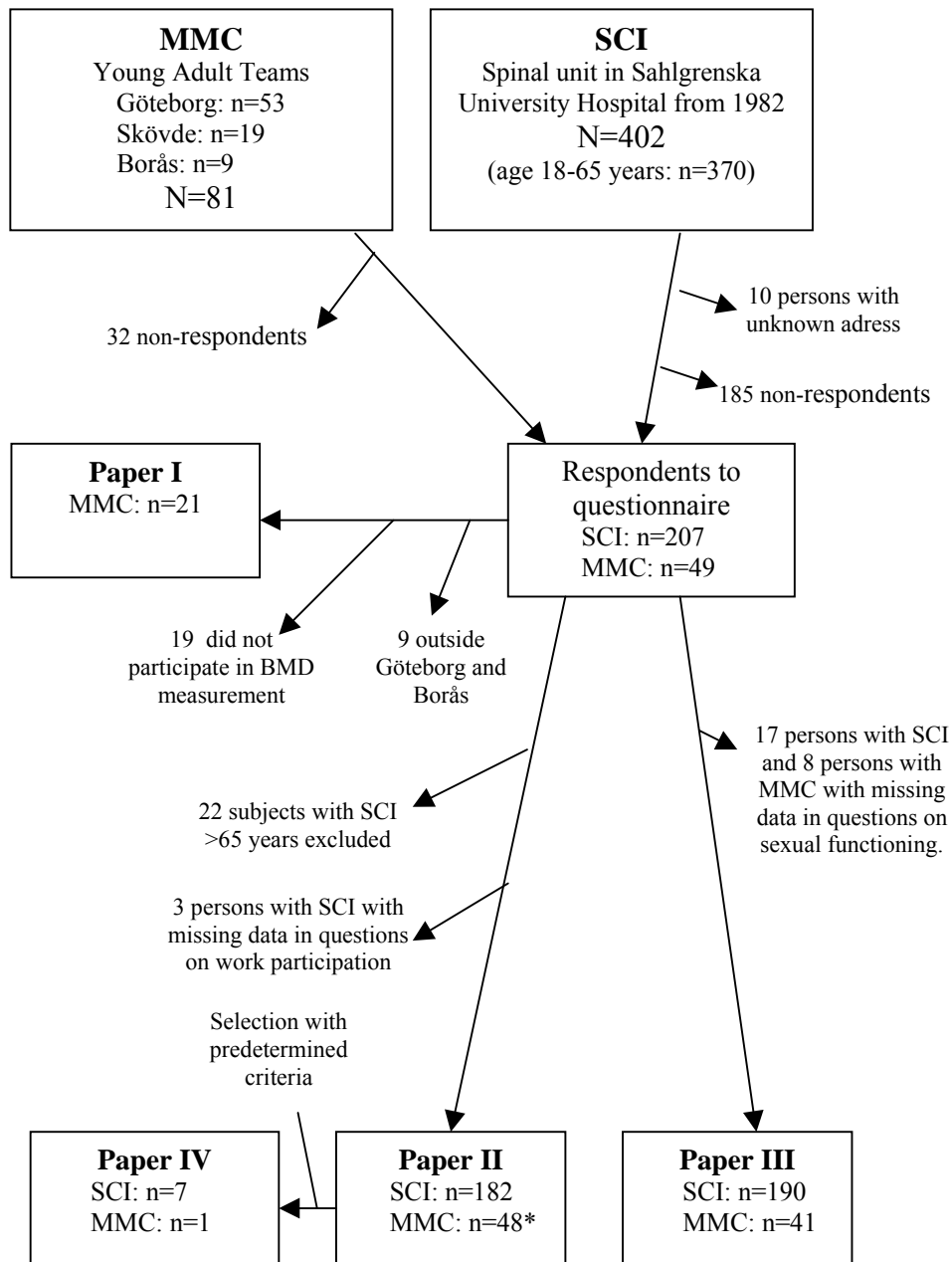
#### 3.1 Study population

The target population comprised persons with traumatic SCI or meningomyelocele living in the county of Western Götaland in Sweden. The county of Western Götaland has ca 1.5 million inhabitants, which is about 18% of the total population in Sweden. All patients with acute traumatic SCI from the County of Western Götaland and the northern part of Halland are referred to the Spinal Injuries Unit in Sahlgrenska University Hospital (personal communication with Ann-Katrin Karlsson, Chief Medical Officer at the Spinal Injury Unit). Likewise, all young adults with MMC from the County of Western Götaland should be admitted to one of the four Young Adult Teams in the region (Göteborg, Borås, Skövde, Vänersborg). Due to several reasons, however, this happens only in ca 90% of cases (personal communication with Kjell Lindquist, Coordinator at the Young Adult Team in Göteborg).

An overview of the study populations in Papers I-IV is shown in Figure 3. The traumatic SCI population consisted of all persons with traumatic SCI between 18 and 75 years who had sustained injury at least 2 years earlier and had been treated in the Spinal Injuries Unit in Sahlgrenska University Hospital, Göteborg, Sweden since 1982 (N=402). The MMC population consisted of all persons with MMC who had been admitted to the Young Adult Teams in Göteborg, Borås and Skövde, Sweden (N=81).

Ten persons with traumatic SCI had unknown address. A structured questionnaire was sent to the remaining 392 persons, of which 207 (52.8%) answered the questionnaire and nine (2.3%) returned an empty questionnaire informing that they could not or were not willing to participate. A somewhat modified questionnaire (e.g. excluding questions on trauma and related factors) was sent to all 81 persons with MMC, of which 49 (60.5%) replied. Two reminders were sent. The characteristics of those who replied (n=207 and n=49) and the non-respondents (n=185 and n=32) are shown in Table 5. The study groups did not differ markedly with regard to gender or neurological level of the injury. The respondents were somewhat older than the non-respondents in the traumatic SCI group.

**Figure 3.** Study populations



\*Due to late return of the questionnaire, one person with MMC could not be included in the work participation study (Paper II). This person was, however, included in the study on satisfaction with sexual life (Paper III).

**Table 5.** Subject characterisation

	Traumatic spinal cord injury		Meningomyelocele	
	Respondents (n=207)	Non-respondents (n=185)	Respondents (n=49)	Non-respondents (n=32)
Gender				
Men	73.9% (n=153)	78.9% (n=146)	53.1% (n=26)	46.9% (n=15)
Women	26.1% (n=54)	21.1% (n=39)	46.9% (n=23)	53.1% (n=17)
Mean age (range)	47.2 (21.8-74.2)	42.6 (19.4-75.3)	30.1 (19.6-50.5)	28.6 (18.4-41.4)
Neurological level <sup>1</sup>				
Cervical	47.8% (n=97)	54.1% (n=72)	.	.
Thoracic	32.0% (n=65)	31.6% (n=42)	.	.
Lumbar/sacral	20.2% (n=41)	14.3% (n=19)	.	.

<sup>1</sup>N=203 for the respondents and n=133 for the non-respondents

Only persons between 18 and 65 years were considered in the study on work participation, leaving a source population of 370 persons with traumatic SCI and n=81 persons with MMC. Three persons with traumatic SCI were excluded from this study because they did not answer the question about current employment status. Thus, the final study group in the study on work participation consisted of 182 (49.2%) persons with traumatic SCI and 48 (59.3%) persons with MMC.

Of those who had responded to the questionnaire, 17 persons with traumatic SCI and 8 persons with MMC were excluded from the study on satisfaction with sexual life because they did not answer the question about satisfaction with sexual life. Thus, the final study group in Paper III consisted of 190 (48.5%) persons with traumatic spinal cord injury and 41 (50.6%) persons with MMC.

All persons with MMC, who had been admitted to the Young Adult Team in Göteborg or Borås, and who had responded to the questionnaire, were invited to take part in the study on osteoporosis in MMC (Paper I). Since 19 persons with MMC, who had been admitted to the Young Adult Team in Skövde, were excluded from this study due to long distances, the source population consisted of 62 persons. Thirty-nine of them (62.9%) responded to the questionnaire, of whom 21 (53.8%) volunteered for clinical examination and measurement of BMD.

The subjects for the study on working conditions (Paper IV) were selected among those who had responded to the questionnaire. The participants were randomly selected among those reporting neck and shoulder pain for more than 30 days during the last 12 month, being younger than 55 years and currently holding at least a half-time job. Furthermore, as the participants would be visited several times, only subjects having their workplace within one hour driving



distance from the research centre were considered. An information letter was sent out to subjects fulfilling the above criteria in order to provide the study with one male and one female subject with MMC, and one male and one female with traumatic SCI at each of the lumbar, thoracic and cervical level. Six subjects with traumatic SCI and one with MMC volunteered to participate in this study. The characteristics of the study group are presented in Table 6.

**Table 6.** Subject characteristics

Case	Gender	Age (years)	Time since injury (years)	Type of lesion	Type of impairment	Ambulatory status	Job seniority (years)
A	F	27	27	MMC	Paraplegia	Non-ambulator	4
B	F	26	5	SCI (L1)	Residual pain syndrome	Ambulator	2
C	F	43	8	SCI (C6)	Complete tetraplegia	Non-ambulator	1
D	M	46	10	SCI (C7)	Incomplete tetraplegia	Non-ambulator	7
E	M	39	10	SCI (T12)	Complete paraplegia	Non-ambulator	6
F	F	31	14	SCI (C6)	Incomplete tetraplegia	Ambulator	5
G	M	36	6	SCI (T4)	Incomplete paraplegia	Non-ambulator	5

### 3.2 Questionnaire

A comprehensive questionnaire was designed after reviewing the literature and consultation with various professionals. The questions were compiled from clinical questionnaires and pilot-tested for correct comprehension in a small group of persons with spinal cord injury.

In terms of International Classification of Functioning, Disability and Health (ICF) the majority of the questions handled body functions and structures, e.g. questions assessing medical problems related to SCL and other disorders. Activities and participation component of ICF was studied by assessing mobility in terms of ambulatory capacity, independence in self-care, and work participation. Some environmental factors were also included into the questionnaire, such as workplace accommodations and bullying.

The data obtained from questionnaire were mainly used in studies on work participation and satisfaction with sexual life. However, background information

needed in the other studies, such as medical conditions and pain, information on life style factors, and working conditions, was also assessed with the questionnaire.

### **3.2.1 Outcomes and predictors (Papers II-III)**

In the study on work participation (Paper II) the main outcome variable was current employment status, which was inquired with a question with several categories. In the analyses a dichotomous variable (participating in work, non-participating in work) was used. Those with full-time or part-time employment, as well as entrepreneurs, were considered as participating in work. Since the number of full-time students was insufficient (n=6 in the traumatic SCI group and n=10 in the MMC group) to keep them as separate groups, they were included in those participating in work, assuming that full-time studies lead to work participation. One person with MMC who was on parental leave was considered as participating in work in the analyses since this person had a permanent job.

In Paper III the main outcome variable was satisfaction with sexual life, which was asked by using a numerical scale from 0 (dissatisfied) to 10 (satisfied). The self-assessed sufficiency of sexual counselling was inquired with a dichotomous question (yes, no).

The independent variables used as potential predictors of work participation and satisfaction with sexual life are presented in Table 7. Quality of life was assessed by using a numerical scale from 0 (dissatisfied) to 10 (satisfied), and satisfaction with current work situation was inquired with a 5-level question (very good, rather good, moderate, rather poor, very poor).

**Table 7. Independent variables**

**Individual factors**

- Gender (1=man, 2=woman)
- Age (years)
- Age at injury (years)
- Time since injury (years)
- Marital status (1=married, 2=co-habiting, 3=single, 4=divorced, 5=widowed)

**Injury-related factors**

- Neurological level (1=cervical, 2=thoracic, 3=lumbar, 4=sacral)
- Presence of brain injury (for subjects with traumatic spinal cord injury) (yes/no)
- Presence of hydrocephalus (for subjects with meningomyelocele) (1=yes, 2=no)
- Ambulatory status (1=community ambulator, 2=functional ambulator, 3=non-functional ambulator, 4=non-ambulator)
- Functional capacity (Self-reported Functional Measure). Need of assistance in the following activities (1=Total help or never do, 2=Some help, 3=Extra time or special tool, 4=No extra time or help)
  - Moving around inside one's house / Going up and down a flight of stairs / Transferring to and from one's bed or chair / Getting on and off the toilet / Transferring from the shower or tub / Eating / Grooming / Taking a bath / Dressing one's upper body / Dressing one's lower body / Toileting / Managing bladder / Managing bowel

**Medical problems related to injury**

- Neuropathic pain –days with pain during the preceding 12 months (1=none, 2=1-7 days, 3=8-30 days, 4=more than 30 days)
- Frequency of urinary incontinence (1=never, 2=sporadic, 3=monthly, 4=weekly, 5=daily)
- Self-assessed inconvenience caused by urinary incontinence (a numerical scale from 0 (no inconvenience) to 10 (high inconvenience))
- Frequency of faecal incontinence (1=never, 2=sporadic, 3=monthly, 4=weekly, 5=daily)
- Self-assessed inconvenience caused by faecal incontinence (a numerical scale from 0 (no inconvenience) to 10 (high inconvenience))
- Spasticity (1=no spasticity, 2=mild spasticity, 3=moderate/severe spasticity affecting functioning, 4=extremely severe spasticity leading to limitations in functioning)
- Presence of decubitus ulcers (1=none, 2=in the buttocks, 3=in the sacrum, 4=in the upper back, 5=in the lower extremities, 6=somewhere else, 7=at several locations)

**Other disorders**

- Somatic disorder
  - Cancer (yes, no)
  - Stroke (yes, no)
  - Epilepsy (yes, no)
  - Pulmonary disease (yes, no)
  - Heart disease (yes, no)
- Mental disorder
  - Mental disorder (yes, no)
  - Eating disorder (yes, no)
- Narcotic abuse
  - Frequency of using (1=never, 2=1-5 times, 3=more than 6 times) the following substances: Marijuana/hashish, Ecstasy, Amphetamine/metamphetamine, Cocaine/crack, Heroin/morphine, Subutex (buprenorphinehydrochloride)/Temgesic (buprenorphinehydrochloride), Other medicines, LSD, Thinner/glue

**Vocational history**

- Education (1=elementary/comprehensive school, 2=vocational school, 3=2-year high school, 4=3-4 - year high school, 5=university/college)
- Employment status at the time of injury (1=full-time employment, 2=part-time employment, 3=entrepreneur, 4=studying, 5=vocational rehabilitation, 6=sick leave >3 months, 7=retired with special agreement, 8=disability pension, 9=military service, 10=parental leave, 11=unemployed)
- Vocational rehabilitation (1=counselling, 2=re-education, 3=on-the-job-training, 4=courses, 5=none)

### **3.3 Clinical examination (Paper I)**

A physician and a physical therapist examined all subjects on the day of the BMD measurement. Information about previous fractures and medications was obtained from the questionnaire. A short interview was performed to complete the data received from the questionnaire. Bladder regime, urinary diversion operations, and chrome EDTA clearance values were obtained from the medical files with the patients' approval.

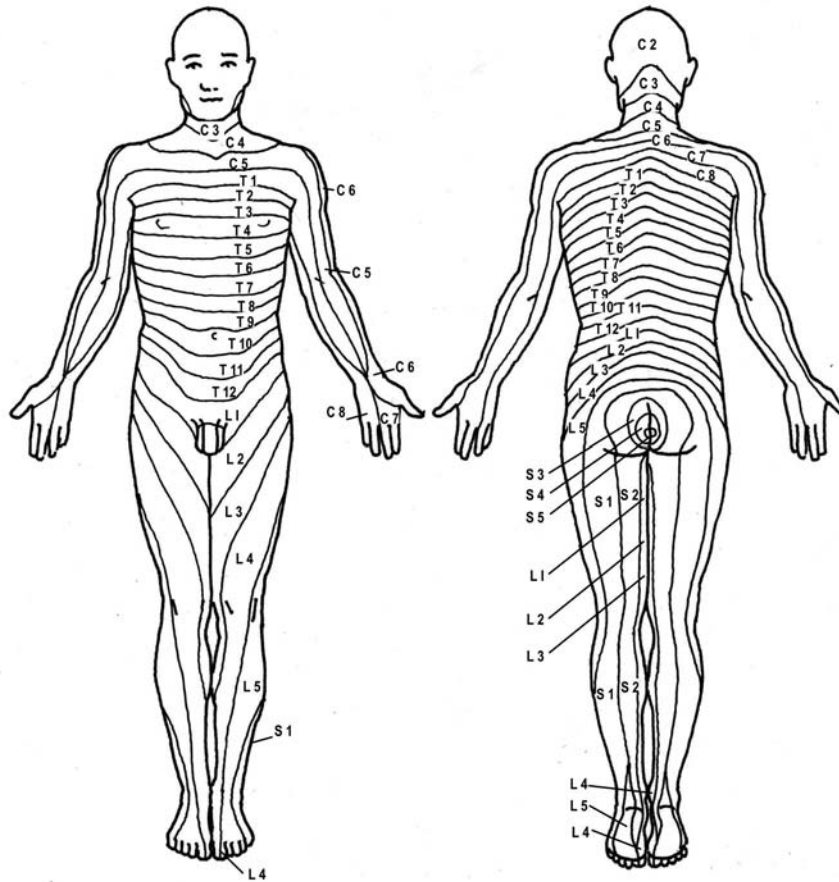
#### **3.3.1 Assessment of ambulatory status**

The present ambulatory status was classified into 4 categories according to Hoffer et al (1973). Community ambulators walked with or without aids and never used a wheelchair. Household ambulators walked inside, but used a wheelchair on longer ambulations. Nonfunctional ambulators walked only in therapy situations, and nonambulators used a wheelchair on all ambulations. For statistical analyses, the subjects were further classified into 2 categories, ambulators (community and household ambulators) and nonambulators (nonfunctional ambulators and nonambulators). History of ambulation was also considered by assessing ambulatory status according to Hoffer et al (1973) at the age of 10 years. Only few (n=5) had changed ambulatory category since the age of 10 and therefore the current ambulatory status was used in the analyses.

#### **3.3.2 Assessment of neurological level of lesion**

The International Standards for Neurological Classification of Spinal Cord Injury by the American Spinal Injury Association (ASIA) were followed to determine the neurologic level of the lesion (Maynard et al. 1997). The ASIA classification is widely used scale for assessing neurological loss or recovery after SCL. The motor and sensory functions are assessed separately. Muscle strengths are graded according to maximum strength attained using a numerical scale from 0 (no movement) to 5 (normal power). The following key muscles are tested (the corresponding neurological level): elbow flexors (C5), wrist extensors (C6), elbow extensors (C7), finger flexors to the middle finger (C8), small finger abductors (T1), hip flexors (L2), knee extensors (L3), ankle dorsiflexors (L4), long toe extensors (L5), and ankle plantar flexors (S1). Sensory function is tested on each dermatome for light and pinprick by using a three-level scale (0=Absent, 1=Impaired or hyperesthesia, 2=Intact). The dermatomes are shown in Figure 4. Rectal examination is performed to check motor function or sensation at the anal mucocutaneous junction. The lesion is defined as complete if both sensory and motor functions in the lowest sacral segments are absent.

**Figure 4.** Dermatomes (Figure by Johanna Paulin)



Neurologic level of lesion is determined by the most caudal level at which both motor and sensory levels are intact, with motor level defined by the most caudal key muscles that have muscle strength of 3 or above while the segment above is normal (=5), and sensory level defined by a sensory score of 2. The ASIA Impairment Scale (AIS) reflects the completeness of the lesion: A = complete (no sensory or motor function is preserved in sacral segments S4-S5), B = incomplete (sensory, but not motor, function is preserved below the neurologic level and extends through sacral segments S4-S5), C = incomplete (motor function is preserved below the neurologic level, and most key muscles below the neurologic level have muscle grade less than 3), D = incomplete (motor function is preserved below the neurologic level, and most key muscles below the neurologic level have muscle grade greater than or equal to 3), and E = normal (sensory and motor functions are normal).

The motor score, which was used to characterise the neurologic level of the lesion, was assessed separately for the upper (0–50) and lower (0–50) extremities to make up variables suitable for testing our hypotheses. The median of the lower-extremity motor score was used to categorise the subjects into 2 groups for analyses. The subjects were categorised into those with full motor capacity in the upper extremities (upper-extremity motor score equal to 50) and those with impairments in upper-extremity motor function (upper-extremity motor score less than 50).

### **3.3.3 Measurement of BMD**

BMD was measured with dual-energy x-ray absorptiometry (DXA) (Delphi W, version 11.2:7; Hologic Inc, 35 Crosby Dr, Bedford, MA 01730-1401). Bone density of the lumbar spine in the L1-4 vertebrae was obtained for 19 patients. The lumbar spine of 2 subjects could not be measured due to prior surgical treatment of scoliosis with Harrington rods. In order to check the reliability of the BMD measurement of the lumbar spine, a radiologist assessed the existence of vertebral arch defects in each one of L1-4 vertebrae. For this purpose, plain radiographs from earlier renography examinations and lumbar spine examinations (e.g. for scoliosis) were used. The radiologist then measured the width of the vertebral arch defect in millimeters. Because a defect in the L1 vertebra was rare, this level was used in the analyses. Furthermore, the values for the L1 vertebra showed high correlation with the total lumbar spine (Spearman  $\rho=.76$ ,  $p=.002$ ). The subjects with defects in all vertebrae were excluded from the analyses of the lumbar spine.

BMD of the left hip was measured in 19 subjects and of the right hip in 13 subjects. Due to technical problems in positioning of the subjects, 1 subject could only be measured on the right side and the hips of 1 subject could not be measured at all. The same radiologist, who checked the reliability of the BMD measurement of the lumbar spine, also determined deformities of the hips from the graphs obtained during the absorptiometry. Subjects with hip deformities in both hips were excluded from the analyses of the BMD of the hip. In the analyses, we mainly used values of the left hip, but for those whose right hip was less deformed than the left hip, the BMD value of the right hip was used. The BMD of the forearm was included in the study protocol from the fifth subject onward and this measurement was obtained for 13 patients. Due to technical problems in the positioning of the subjects, 4 subjects could not be measured in the forearm.

When assessing BMD both T and Z scores were considered. A T score is the number of SDs the BMD value is above or below that of the young adult mean of the reference population. A Z score is the number of SDs the BMD value is above or below that of the age-matched mean of the reference population. Since

the study population was relatively young, there were no major differences between the T score and Z score, and a decision was made to use the T score in the analyses. Furthermore, using T score is consistent with diagnostic criteria for osteoporosis established by World Health Organization (WHO). According to them, the diagnosis of osteoporosis is made when the T score for BMD falls  $-2.5$  SDs or more below that for the young adult mean of the reference population. When the value for BMD falls between  $-1.0$  and  $-2.5$  SDs below the young adult mean, the bone is defined as osteopenic. A North American reference population provided by the manufacturer was used.

#### **3.3.4 Blood samples**

To assess bone mineral metabolism, as well as renal function, venous blood samples were obtained for analyses of the levels of osteocalcin, parathyroid hormone (PTH), 25-hydroxyvitamin D ( $25[\text{OH}]\text{D}_3$ ), total calcium, ionized calcium, standard bicarbonate, cystatin C, and bone-specific alkaline phosphatase. Serum calcium, ionized calcium, and standard bicarbonate were assessed with standard methods. Serum osteocalcin was assessed by radioimmunoassay, PTH with immunochemiluminometry, and cystatin C with turbidimetry. Blood samples were obtained from 16 subjects.

#### **3.4 Workplace intervention (Paper IV)**

Each participant was visited at the workplace where an ergonomist made an evaluation of the workplace layout, work postures, and work technique. The working situations were classified on a red-yellow-green scale, where red and yellow indicated situations of concern. The ergonomist also made video recordings of the subject at work. This not only included a number of typical working situations, but also the subject entering the building and getting to the workplace, visiting the restroom and facilities for coffee and lunch breaks. These video recordings were then evaluated by means of VIDAR (Forsman et al. 2003), a video-based method for self-evaluation. In this method the subject watches him/herself and is asked to identify physically and psychosocially demanding situations. When a physically demanding situation is identified, the subject reports body parts with discomfort and rates the discomfort on Borg's CR-10 scale. A two-level questionnaire is used for the psychosocial characteristics.

All subjects were offered to take part in a myofeedback intervention (Hermens and Hutten 2002), aiming at reducing muscle load of the neck and shoulder muscles. This is a biofeedback based method using the myoelectric activity from the trapezius muscle as the physiological signal analysed and fed back to the subject. However, contrary to conventional myofeedback, in which feedback is

given when the myoelectric activity crosses a threshold level, the current method evaluates the relative rest time (RRT), i.e. the fraction of time where the muscle has been in a rest-like condition. The equipment used consists of a harness where the electrodes for picking up the muscle activity are placed. This way the subjects can don and doff the system themselves, making the use of the system fully self-administered. The myoelectric signal from the electrodes is fed to a control unit which makes the evaluation and gives an auditory alarm when the alarm criteria are fulfilled. The myofeedback intervention also implies the subjects to keep a diary of work activities and musculoskeletal problems in order to make comparisons of recorded muscle activity in relation to the work performed and problems experienced.

The evaluation battery described above was applied during a number of visits during a time period of one to three months. The first visit included filling out the questionnaires, performing the ergonomist's evaluation, the video recording, and the VIDAR evaluation. The questionnaires used were the QPSNordic34+ (Lindström et al. 2000) and a form for the reporting of pain in the neck/shoulder and upper limbs by means of an interval scale from 0 (no pain) to 10 (worst imaginable pain). The myofeedback method was also presented and a decision was made whether the subject would try to use this method or not. When problems were identified that required more than modest investments, or measures were planned that would not be restricted to the person's own workplace, a meeting with the employer and/or the Swedish Social Insurance Agency was also arranged.

Extra visits were scheduled for those interested in taking part in the myofeedback intervention. This started with laboratory tests to establish a baseline of muscle activation during three computer related tasks. These computer based tasks (Sjøgaard et al. 2006), which were performed in random order, were a text input/editing task, a stress provocation task (the Stroop test (Laursen et al. 2002)), and a precision task (Birch et al. 2000). After four weeks of myofeedback training these tests were repeated in order to document any changes in muscle activation during computer related work. Between the baseline and follow-up recordings each of the myofeedback users was visited every week in order to discuss experiences during the previous week and to compare the recorded muscle activity profiles of the trapezius muscle with information from the diary. This way situations leading to unfavourable muscle activation could be identified and alternative solutions to these situations discussed.

During the final visit the implemented changes were documented by video. The QPSNordic34+ questionnaire and the form for the reporting of pain in the neck/shoulder and upper limbs were repeated.



Finally, a few weeks after the final visit, a follow-up interview aiming to gather the participants' experiences from the intervention process and the effects of the changes, was done by phone by a researcher not earlier involved in the study.

### **3.5 Statistical analyses**

Statistical analyses were carried out with SPSS version 12.0.1 statistical software. Statistical significance was defined as  $p < 0.05$ .

#### ***Paper I***

The results were given as T scores for BMD at the measured locations. Logistic regression model was applied to assess risk of osteoporosis in at least one of the measured sites. Due to a limited number of subjects only univariate models could be calculated. Other analyses were carried out using absolute BMD values (in  $\text{g}/\text{cm}^2$ ) as a continuous variable as the outcome. General linear models (analysis of variance) were used to study the effects of ambulatory status and medical risk factors on BMD. The interaction between ambulatory status and medical risk factors was included into the models.

#### ***Paper II***

The traumatic SCI group and the MMC group were analysed separately. We looked first at the univariate association between each independent variable and the outcome. Univariate logistic regression models were calculated separately for the men and women in the traumatic SCI group. In the MMC group the men and women were kept together in the analyses, due to a small number of participants. Odds ratios (OR) with 95% confidence intervals (CI) were computed. Due to the limited number of participants with MMC and women with traumatic SCI the multivariable modelling was carried out only for the men with traumatic SCI. The final logistic model was fitted by using risk factors of primary interest that had shown association in the preliminary analyses. The goodness of fit of the model was evaluated by the Hosmer & Lemeshow's method (Hosmer and Lemeshow 1989). The Mann-Whitney test was used to test differences in quality of life (Altman 1991).

#### ***Paper III***

The normality of distribution of all variables was tested by using the Kolmogorov-Smirnov test (Armitage and Berry 1994). Most of our variables showed a skewed distribution. Therefore Spearman rank correlation was used in preliminary analyses to investigate the associations between our outcome and the predictors (Armitage and Berry 1994). Correlation coefficients with p-values were computed. The Mann-Whitney U -test was used for all dichotomised predictors (Armitage and Berry 1994). The Mann-Whitney U -test was used also to test differences between the men and women in satisfaction with sexual life

and inconvenience caused by urinary or faecal incontinence, as well as differences in satisfaction with sexual life between the traumatic SCI and MMC group.

For the group with traumatic SCI the outcome, satisfaction with sexual life showed a skewed distribution. Even the transformations did not make the distribution normal (logarithmic, square root transformation). Therefore we used logistic regression modelling for this group (Armitage and Berry 1994). The participants were classified into two groups using the median value of 3 for sexual satisfaction as the cut-off point. Age and gender adjusted odds ratios (OR) with 95% confidence intervals (CI) were computed. The final logistic model was run for the persons with traumatic SCI by using modifiable risk factors of primary interest that had shown association in the preliminary analyses in addition to age and gender. For the group with MMC the outcome showed a normal distribution. Therefore, general linear model was used to model sexual satisfaction in this group.

#### ***Paper IV***

The Wilcoxon signed rank sum test was used to test for difference between neck and shoulder pain at the baseline and the follow-up (Altman 1991). Paired samples t-test was used to test for differences in RRT times between the baseline and follow-up (Altman 1991).

#### **3.6 Ethics**

The study was approved by the Ethics Committee of Göteborg University.

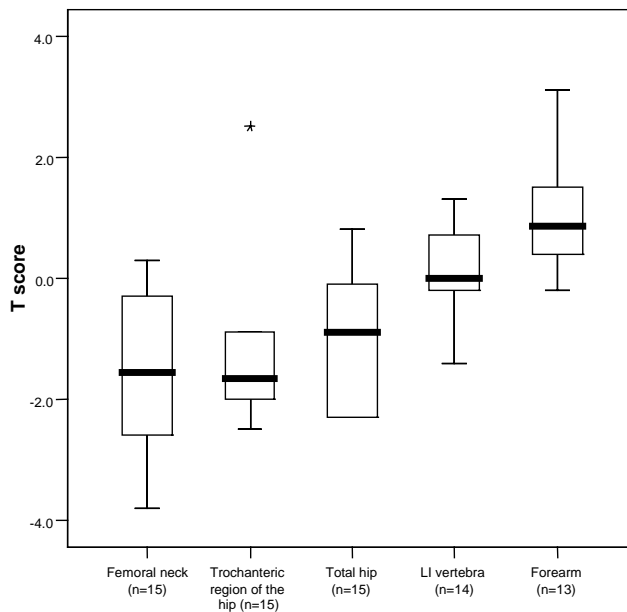
## 4. RESULTS

### 4.1 Paper I

#### 4.1.1 Prevalence of osteoporosis in MMC

The T scores for BMD in the measured locations are given in Figure 5. Because the L1 vertebra was nearly always free of bone defect, the BMD of the L1 vertebra is reported, instead of the lower vertebrae or of the total lumbar spine. After the exclusion of those 6 with bone defect in the L1 vertebra the bone density of the lumbar spine was osteopenic in 3 of 14 (21%) subjects and osteoporotic in 2 (14%) subjects. After the exclusion of 5 subjects with hip deformities, 9 (60%) subjects had osteopenia and none had osteoporosis in the total hip, but when the BMD in the femoral neck and trochanteric region of the hip was scrutinised, as many as 7 (47%) subjects could be considered to have osteoporosis in either site. The bone density of the forearm was nearly always within normative limits and only 3 (23%) patients showed osteopenia and no one osteoporosis. Seven of the total of 21 (33%) subjects had osteoporosis in at least 1 of the measured sites.

**Figure 5.** Medians (bold lines) with lower and upper quartiles (lower and upper edge of boxes) and range (whiskers) for T scores of bone mineral density



\* Extreme value in one individual. A value more than three interquartile ranges from the upper or lower edge of the box.

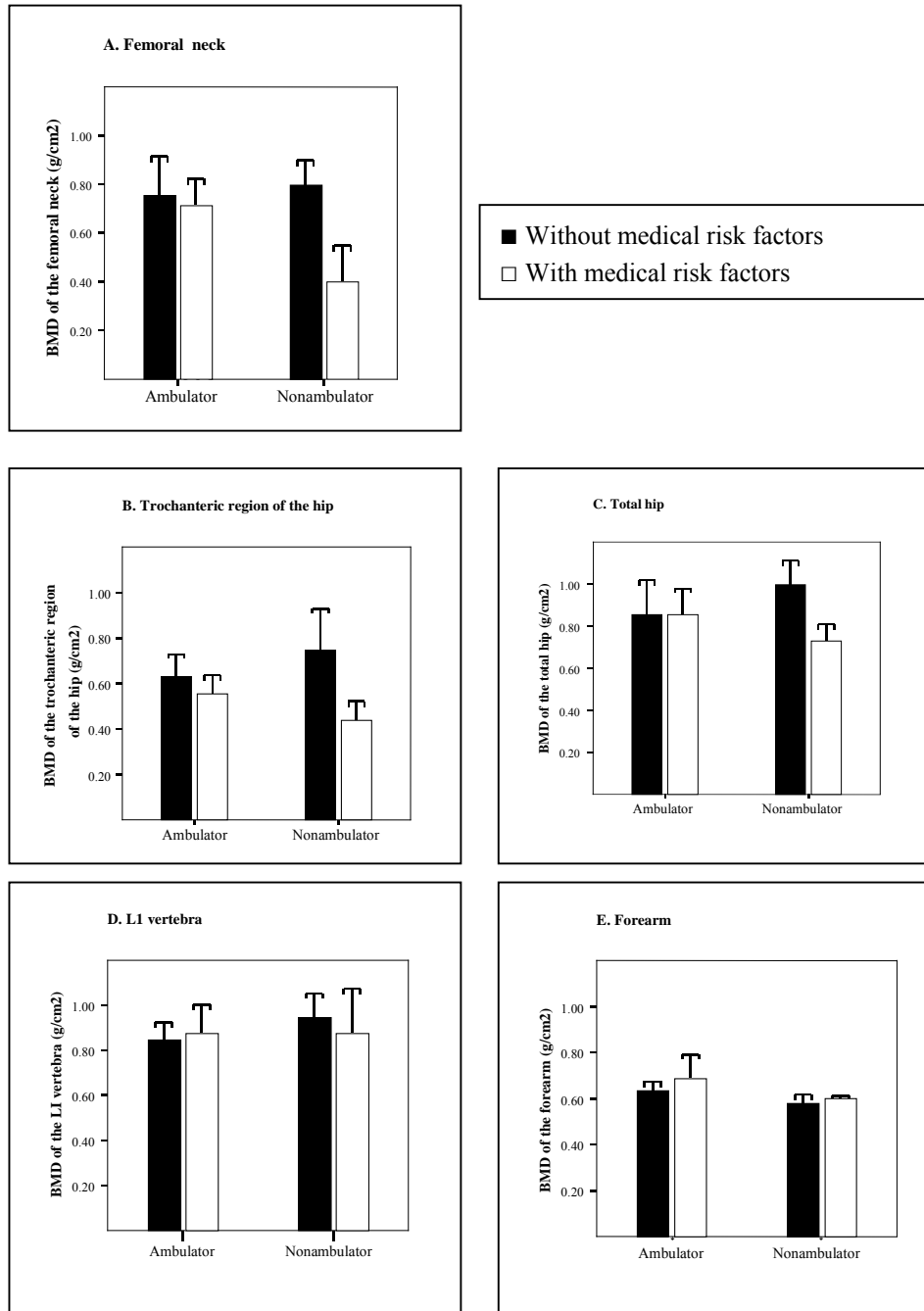
#### 4.1.2 Risk factors of osteoporosis in MMC

Sex, chronological age, body mass index (BMI), lower-extremity motor score, upper-extremity motor score, or ambulatory status had no effect on the risk for osteoporosis in at least one of the measured sites. Odds ratio for all medical risk factors combined was 9.60 (confidence interval, 0.88–105.17). The risk of osteoporosis in at least one of the measured sites did not differ between those with and without previous fractures.

The absolute values of BMD according to ambulatory status and other medical risk factors for osteoporosis are shown in Figure 6. When the effect of ambulatory status on BMD was studied without considering possible effect of other medical risk factors, the ambulators showed higher BMD values in the forearm than the nonambulators ( $F=5.2$ ,  $p=.043$ ). A similar tendency was seen in the femoral neck but this difference was not statistically significant ( $F=3.3$ ,  $p=.094$ ). Ambulatory status alone had no effect on BMD in the trochanteric region of the hip, total hip, or lumbar spine.

Twelve subjects had one or more medical risk factors for osteoporosis (urinary diversion with ileum resection, renal insufficiency, medication for epilepsy, oral corticosteroid treatment, diagnosis of Down syndrome). Among 13 nonambulators 7 had at least one other medical risk factor for osteoporosis and among 8 ambulators 5 had at least one other medical risk factor. When both ambulatory status and other medical risk factors for osteoporosis were studied in the same model, ambulatory status alone no longer had an effect on BMD (Table 8). The presence of other medical risk factors, in contrast, had a significant effect on the BMD of the femoral neck and trochanteric region of the hip so that those with at least one other medical risk factor showed lower BMD at these locations than the others. A similar tendency was seen in the BMD of the total hip, but this difference was not statistically significant. The presence of other medical risk factors had no effect on the BMD of the L1 vertebra or the forearm (Figure 6, Table 8).

**Figure 6A-E.**



The effect of medical risk factors on BMD of the femoral neck, trochanteric region of the hip, and total hip seemed to be stronger in nonambulators than in ambulators (Figure 6). This interaction was statistically significant for the femoral neck, but not for the total hip or trochanteric region of the hip. No such interaction was seen in the BMD values for the L1 vertebra or the forearm (Table 8).

**Table 8.** Effects of ambulatory status, medical risk factors, \* and their interactions on BMD at various locations (Analysis of variance table for the data in Figure 6)

Source of variation	Measured location									
	Femoral neck		Trochanteric region of the hip		Total hip		L1 vertebra		Forearm	
	F	p	F	p	F	p	F	p	F	p
Ambulatory status	3.7	.082	0.0	.999	0.0	.885	0.4	.546	3.3	.101
Medical risk factors*	9.4	.011	10.7	.007	4.5	.058	0.1	.801	0.9	.359
Ambulatory status by medical risk factors*	6.4	.028	3.8	.076	4.6	.054	0.4	.550	0.2	.648

\*One or more of the following: urinary diversion, renal insufficiency, medication for epilepsy, oral cortisone treatment for more than 3 months, and diagnosis of Down syndrome.

## 4.2 Paper II

### 4.2.1 Work participation

#### *SCI*

Forty-eight percent of the men (n=64) and 46% of the women (n=22) were employed. Three percent (n=4) of the men and four percent (n=2) of the women were studying. The majority of the subjects had office work in administration or dissemination of information (50 of 77). Thirteen persons were employed within manufacturing, seven within health service, and three within service industry.

#### *MMC*

Twenty-eight percent (n=7) of the men and 52% (n=12) of the women with MMC were employed. Twenty-four percent (n=6) of the men and 17% (n=4) of the women were studying. The type of industry was most often administration (8 of 19). Four persons were employed within health service, three within dissemination of information, two within service industry, and two within manufacturing.

#### 4.2.2 Predictors of work participation

##### *SCI*

In the univariate models the risk of non-participation in work was increased for the men older than 55 years. In the women there was no association between age and work participation. In the men the risk of non-participation in work was higher among those who had sustained injury at an age older than 40 years, whereas age at injury did not affect work participation among the women. There was a tendency for the men injured more than ten years ago to be more often at work than those with more recent injuries. Dichotomising time since injury at 10 years gave an OR of 0.49 (CI 0.24, 1.03). In the women time since injury did not affect work participation (Table 9).

Neurological level or ambulatory status did not affect work participation in the men or in the women with traumatic SCI (Table 9). Additional analyses of ambulatory status controlling for neurological level did not show differences in work participation between ambulating and non-ambulating subjects either in the men or the women. There was a tendency for brain injury to increase the risk of non-participation in work among the men with traumatic SCI. Among the women there were only two subjects with brain injury and neither of these was participating in work. A low Self-reported Functional Measure score increased the risk of non-participation both in the men and women (Table 9).

Neuropathic pain increased the risk of non-participation in work in the men but not in the women. Neither urinary nor faecal incontinence was associated with work participation. However, among the women there were only two subjects who suffered from faecal incontinence weekly or daily and neither of these women was at work. The presence of other somatic or mental disorder increased the risk of non-participation in work in the men. Also among the women those with other somatic disorder tended to participate in work less frequently than those without other somatic disorder. The presence of mental disorder did not affect work participation in the women. Narcotic abuse showed no effect either in the men or the women (Table 9).

The men with primary level education tended to participate less frequently in work than the men with higher educational level. None of the eight women who had only primary level education were participating in work. The risk of non-participation in work seemed to be increased, although not statistically significantly, among the men who were not at work at the time of injury when compared with those who were working at the time of injury. There were only two women who were not at work at the time of injury and neither of them was at work at the time of the study (Table 9).

**Table 9.** Risk of non-participation in work in subjects with traumatic spinal cord injury (n=164-182) and meningomyelocele (n=41-48). Univariate associations from logistic regression modelling (OR=Odds Ratio, CI=Confidence Interval).

		Traumatic spinal cord injury		Meningomyelocele
		Men	Women	
		OR (95 % CI)	OR (95 % CI)	OR (95 % CI)
<b>Subject characteristics</b> (n=SCI men/SCI women/MMC)				
Age (years)	≤35 (n=27/15/33)	1.00	1.00	1.00
	36-45 (n=40/12/12)	0.40 (0.14, 1.10)	0.89 (0.19, 4.00)	0.24 (0.05, 1.27)
	46-55 (n=35/9/3)	0.55(0.20, 1.52)	1.09 (0.21, 5.76)	2.40 (0.20, 29.13)
	>55 (n=32/12/0)	5.01 (1.49, 16.93)	0.63 (0.14, 2.89)	.
Age at injury (years)	<25 (n=57/20)	1.00	1.00	.
	25-40 (n=46/14)	1.10 (0.50, 2.45)	0.75 (0.19, 2.96)	.
	>40 (n=29/13)	10.71(3.28, 35.04)	1.17 (0.29, 4.73)	.
Time since injury (years)	<10 (n=45/15)	1.00	1.00	.
	10-20 (n=56/24)	0.50 (0.23, 1.11)	0.48 (0.13, 1.77)	.
	>20 (n=31/8)	0.48(0.19, 1.22)	0.67 (0.12, 3.76)	.
<b>Injury-related factors</b>				
Neurological level	Thoracic/lumbar/sacral (n=69/26)	1.00	1.00	.
	Cervical (n=63/22)	1.35 (0.68, 2.68)	1.97 (0.62, 6.24)	.
Brain injury / hydrocephalus	No (n=112/42/10)	1.00	1.00	1.00
	Yes (n=8/2/38)	3.46 (0.67, 17.90)	.	1.70 (0.38, 7.59)
Ambulatory status	Community ambulator (n=35/17/9)	1.00	1.00	1.00
	Functional ambulator (n=8/3/9)	4.50 (0.79, 25.57)	.	2.29 (0.17, 30.96)
	Non-ambulator (n=85/28/30)	1.40 (0.63, 3.11)	1.03 (0.31, 3.43)	9.14 (1.01, 82.44)
SRFM	Sum score >46 (n=59/21/25)	1.00	1.00	1.00
	Sum score ≤46(n=59/21/21)	3.57 (1.66, 7.64)	8.53 (2.16, 33.72)	10.50 (2.58, 42.68)
<b>Medical problems related to injury</b>				
Neuropathic pain	≤ 30 days (n=66/21)	1.00	1.00	.
	> 30 days (n=63/24)	2.66 (1.31, 5.42)	1.10 (0.34, 3.55)	.
Urinary incontinence	Never (n=37/17/12)	1.00	1.00	1.00
	Sporadic / Monthly (n=53/17/19)	1.22 (0.53, 2.83)	1.00 (0.26, 3.85)	1.75 (0.35, 8.71)
	Weekly / Daily (n=42/12/15)	1.18 (0.49, 2.85)	0.44 (0.10, 2.06)	3.43 (0.66, 17.93)
Faecal incontinence	Never (n=34/20/10)	1.00	1.00	1.00
	Sporadic / Monthly (n=87/24/27)	1.73 (0.77, 3.89)	1.22 (0.37, 4.02)	1.60 (0.34, 7.60)
	Weekly / Daily (n=11/2/8)	1.94 (0.49, 7.66)	.	2.33 (0.34, 16.18)
<b>Other disorders</b>				
Somatic disorder	No (n=117/40/39)	1.00	1.00	1.00
	Yes (n=13/7/9)	3.71 (1.13, 12.19)	4.81 (0.88, 26.30)	2.24 (0.61, 8.16)
Mental disorder	No (n=111/37/39)	1.00	1.00	1.00
	Yes (n=15/10/9)	5.25 (1.40, 19.65)	1.06 (0.26, 4.27)	1.28 (0.30, 5.54)
Narcotic abuse	No (n=110/46/46)	1.00	1.00	.
	Yes (n=18/2/1)	1.75 (0.63, 4.86)	1.00 (0.06, 16.97)	.
<b>Vocational history</b>				
Education	Tertiary level (n=34/27/9)	1.00	1.00	1.00
	Secondary level (n=75/13/32)	1.39 (0.61, 3.16)	2.33 (0.60, 9.02)	5.47 (0.61, 49.17)
	Primary level (n=22/8/6)	2.06 (0.79, 6.14)	.	40.00 (2.01, 794.27)
Employment status at the time of injury*	At work (n=90/30)	1.00	1.00	.
	Studying (n=6/3)	0.18 (0.02, 1.63)	2.29 (0.19, 27.99)	.
	Not at work (n=7/2)	5.49 (0.64, 47.46)	.	.
Vocational rehabilitation	Yes (n=45/19/12)	1.00	1.00	1.00
	No (n=84/28/30)	2.19 (1.04, 4.62)	1.11 (0.35, 3.57)	0.70 (0.18, 2.77)

\* Only subjects older than 20 years at the time of injury are included



The multivariable models for men were first run including age, Self-Reported Functional Measure, neuropathic pain, presence of other somatic disorder, presence of mental disorder, and vocational rehabilitation. In this model, the OR for somatic disorder that was positive in the univariate model changed to negative. A further scrutiny revealed that this change occurred when somatic disorder was modelled together with age, mental disorder, and Self-Reported Functional Measure. This suggested correlation between somatic disorder and the mentioned variables or the combination of them. Therefore, to avoid multicollinearity, we omitted somatic disorder from the final model. In the final multivariable model only age older than 55 years and presence of mental disorder remained statistically significant risk factors of non-participation in work. The effect of Self-Reported Functional Measure approached statistical significance (Table 10).

**Table 10.** Risk of non-participation in work from multivariable logistic regression model in the men with traumatic spinal cord injury (OR=Odds Ratio, CI=Confidence Interval).

		<b>OR</b>	<b>95% CI</b>
Age (years)	≤ 35	1.00	
	36-45	0.36	(0.10, 1.31)
	46-55	0.32	(0.08, 1.24)
	> 55	5.67	(1.14, 28.23)
Self-reported functional measure	Sum score > 46	1.00	
	Sum score ≤ 46	2.60	(0.98, 6.89)
Neuropathic pain	≤ 30 days	1.00	
	> 30 days	2.07	(0.74, 5.76)
Mental disorder	No	1.00	
	Yes	5.27	(1.06, 26.17)
Vocational rehabilitation	Yes	1.00	
	No	1.42	(0.49, 4.05)

Hosmer & Lemeshow goodness of fit test:  $p=.38$  (Hosmer and Lemeshow 1989).

### **MMC**

Age did not affect work participation among the subjects with MMC, neither did concomitant hydrocephalus. Use of a wheelchair for ambulation as well as a low Self-Reported Functional Measure score increased the risk of non-participation markedly. No significant association was found between frequency of urinary or faecal incontinence and work participation. The presence of somatic or mental disorders did not affect work participation among persons with MMC. Narcotic abuse could not be analysed properly due to a small number of users. However, the only person with MMC who was classified as a narcotic abuser was not at work. Primary level of education as the highest educational level reached increased the risk of non-participation in work (Table 9).

### **4.2.3 Obstacles for work participation**

#### ***SCI***

The reason most often reported as an obstacle for work participation among the persons with traumatic SCI was the severity of the injury (reported by 70% of the men and 50% of the women). Nearly half of the participants considered injury-related medical problems and health problems as hinders for their work participation. Thirty percent reported lack of motivation as a hinder for their work participation. Nearly half (38 of 84) of those who were currently employed reported that some changes had been made at their work place to improve accessibility. Five persons considered these changes as insufficient and another five persons had been forced to change workplace due to problems with accessibility.

#### ***MMC***

A lack of employment possibilities was most often reported as an obstacle for work participation (reported by 44% of the men and 57% of the women). Thirty-three percent of the men and 43% of the women considered health problems as a hinder for their work participation. Thirty percent of the men but none of the women considered lack of motivation as a hinder for their work participation. Half (9 of 18) of those who were currently employed reported that some changes had been made at their work place to improve accessibility. Two persons considered these changes as insufficient and one person had been forced to change workplace due to problems with accessibility.

### **4.2.4 Bullying**

Eight percent (n=9) of the men and 5% (n=2) of the women with traumatic SCI reported that they had been bullied at work. In the majority of cases (7 of 11) the bullying was due to the person's functional impairments.

Six percent (n=1) of the men and 14% (n=3) of the women with MMC reported that they had been bullied at work. Two of the women who had been bullied reported that bullying had been due to their functional impairments.

### **4.2.5 Satisfaction with current work situation**

In the traumatic SCI group 79% (50 of 63) of the men and 81% (17 of 21) of the women rated satisfaction with their current work situation as very or rather good. Those participating in work reported better quality of life than the non-participants. This was seen both for men and women (Mann Whitney U test, p=.001 and p=.018, respectively).

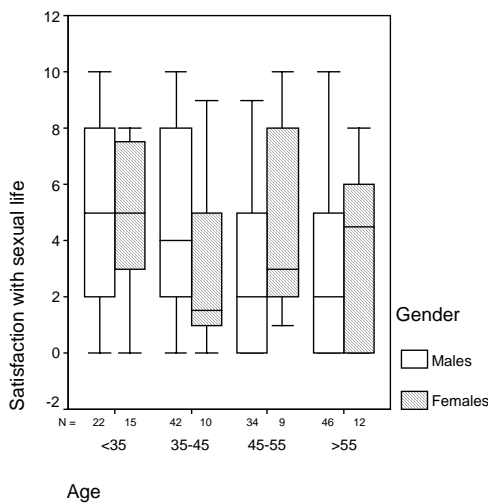
Fifty-seven percent (n=4) of the men and 83% (n=10) of the women with MMC rated satisfaction with their current work situation as very or rather good. There was no significant association between current work participation and quality of life either in the men or in the women with MMC.

### 4.3 Paper III

#### 4.3.1 Satisfaction with sexual life

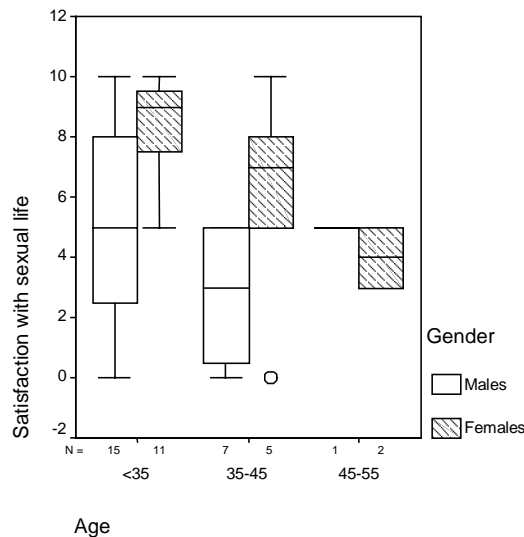
In the persons with traumatic spinal cord injury the median of satisfaction with sexual life was 3, (25<sup>th</sup> percentile (Q1) was 0.25 and 75<sup>th</sup> percentile (Q3) was 6) for the men and 4 (Q1=1, Q3=7) for the women. The mode was 0 for both genders. The gender difference in the medians was not statistically significant (Mann-Whitney, p=.325). Satisfaction with sexual life declined with age in the men but not in the women (Spearman's rho -.30, p<.001, and -.11, p=.474, respectively) (Figure 7).

**Figure 7.** Medians (bold lines) with lower and upper quartiles (lower and upper edge of boxes) and range (whiskers) for satisfaction with life according to age and gender in persons with traumatic spinal cord injury.



In the MMC group the median of satisfaction with sexual life was 5 (Q1=1, Q3=8) for the men and 8 (Q1=5, Q3=9.25) for the women. This difference was statistically significant (Mann-Whitney,  $p=.009$ ). Satisfaction with sexual life tended to decline with increasing age (Spearman's  $\rho = -.30$ ,  $p=.055$ ) (Figure 8).

**Figure 8.** Medians (bold lines) with lower and upper quartiles (lower and upper edge of boxes) and range (whiskers) for satisfaction with life according to age and gender in the persons with MMC.



#### 4.3.2 Predictors of satisfaction with sexual life

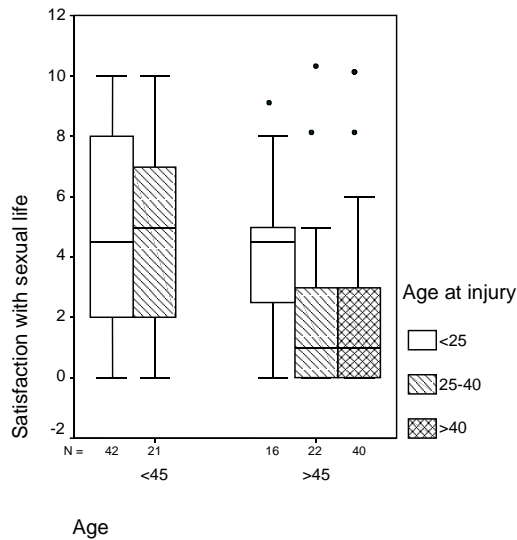
##### *SCI*

Sixty-nine percent of the men and 59 % of the women with traumatic SCI reported that they had received enough sexual counselling. There was no association between the time since injury and the self-assessed sufficiency of sexual counselling (Spearman's  $\rho = -.08$ ,  $p=.306$ ). Those who reported the amount of sexual counselling as sufficient showed higher satisfaction with their sexual life than the others (Mann-Whitney,  $p=.004$ ).

In the men sexual dissatisfaction was higher among those who had sustained injury at an older age, whereas no association between these two variables was seen in the women (Spearman's  $\rho = -.27$ ,  $p=.001$ , and  $.01$ ,  $p=.949$ , respectively). Furthermore, as shown in Figure 9, age at injury had minor importance among the men younger than 45 years. Among the men older than 45 years, those who had sustained their injury at an age higher than 25 years, had a higher risk of sexual dissatisfaction. This interaction did not, however, reach statistical significance (OR 3.30, 95% CI 0.70-15.74,  $p=.135$ ). There was no association

between the time since injury and satisfaction with sexual life (Spearman's rho = .001, p=.991).

**Figure 9.** Medians (bold lines) with lower and upper quartiles (lower and upper edge of boxes) and range (whiskers) for satisfaction with life according to age and age at injury in the men with traumatic SCI.



\* Extreme value in one individual. A value more than three interquartile ranges from the upper or lower edge of the box.

There seemed to be no association between neurological level and satisfaction with sexual life (Spearman's rho = -.001, p=.991). However, in a univariable logistic model run with the men, the persons with cervical injury were more satisfied with their sexual life than the persons with lower injuries (OR 0.47, 95% CI 0.24-0.93). On the contrary, the female participants with cervical injuries tended to be less satisfied than the women with lower injuries (OR 2.71, 95% CI 0.81-9.06).

Forty-seven percent of the men and 56% of the women had experienced neuropathic pain on more than 30 days during the preceding 12 months. Neuropathic pain increased sexual dissatisfaction in the men with traumatic SCI but not in the women (Spearman's rho = -.23, p=.006, and -.08, p=.061, respectively)

In the participants with traumatic SCI the median of self-assessed inconvenience caused by urinary incontinence was 5 (Q1=1, Q3=8) for the men and 3 (Q1=0, Q3=7) for the women. The median of self-assessed inconvenience

caused by faecal incontinence was 5 (Q1=1, Q3=7.5) for the men and 3 (Q1=0, Q3=7) for the women. Neither of the gender differences in the medians was statistically significant (Mann-Whitney,  $p=.285$ , and  $p=.066$ , respectively). Those reporting more inconvenience from urinary incontinence were more dissatisfied with their sexual life than the others (Spearman's  $\rho = -.19$ ,  $p=.009$ ). This association, however, was significant only for the men and not for the women (Spearman's  $\rho = -.19$ ,  $p=.021$ , and  $-.18$ ,  $p=.236$ , respectively). Inconvenience caused by faecal incontinence increased sexual dissatisfaction (Spearman's  $\rho = -.24$ ,  $p=.001$ ). This association, however, was seen only in the men and not in the women (Spearman's  $\rho = -.26$ ,  $p=.002$  for the men, and  $-.18$ ,  $p=.269$  for the women).

Spasticity was reported by 75 % of the participants and 39 % reported that spasticity affected their functioning. The association between spasticity and satisfaction with sexual life did not reach statistical significance (Spearman's  $\rho = -.14$ ,  $p=.060$ ).

Thirteen percent had a decubitus ulcer in at least one body area. Fourteen men and two women had a decubitus ulcer in the sacrum or buttocks, or at several locations. There was no association between decubitus ulcers and satisfaction with sexual life (Mann-Whitney,  $p=.073$ ).

Fifty-six percent of the men and 52 % of the women with traumatic SCI were married or co-habiting. Sixteen percent of the men and 26% of the women were divorced. There was no association between marital status and satisfaction with sexual life (Mann-Whitney,  $p=.179$ ).

In the age and gender adjusted logistic regression models age, neuropathic pain, inconvenience caused by urinary or faecal incontinence, and self-assessed sufficiency with sexual counselling seemed to predict the risk of sexual dissatisfaction. The final multivariable model was planned to be run with all these predictors. However, inconvenience caused by urinary incontinence and inconvenience caused by faecal incontinence showed high correlation. Therefore, the two variables were not included in the same model to avoid multicollinearity. Likewise, neuropathic pain was correlated both with urinary and faecal incontinence and could therefore not be fitted in the same model. Three different models were therefore run. In these final multivariable models both inconvenience caused by urinary and faecal incontinence as well as neuropathic pain remained statistically significant risk factors of dissatisfaction with sexual life. Even moderate inconvenience caused by incontinence, either urinary or faecal, increased the risk of sexual dissatisfaction (Table 11).

**Table 11.** Risk of dissatisfaction with sexual life. Multivariable logistic regression models in the persons with traumatic SCI (OR=Odds Ratio, CI=Confidence Interval).

a) Model including age, gender, inconvenience caused by urinary incontinence, and self-assessed sufficiency of sexual counselling (n=178)

Predictor		OR	95 % CI	p
Age	< 45 years	1.00		
	> 45 years	2.85	(1.46, 5.56)	0.002
Gender	Female	1.00		
	Male	1.22	(0.57, 2.63)	0.605
Inconvenience caused by urinary incontinence	Low (0-2)	1.00		
	Median (3-6)	3.21	(1.30, 7.93)	0.012
	High (7-10)	2.53	(1.21, 5.29)	0.013
Self-assessed sufficiency of sexual counselling	Yes	1.00		
	No	2.45	(1.22, 4.92)	0.012

Hosmer & Lemeshow goodness of fit test: p=0.56 (Hosmer and Lemeshow 1989)

b) Model including age, gender, inconvenience caused by faecal incontinence, and self-assessed sufficiency of sexual counselling (n=176)

Predictor		OR	95 % CI	p
Age	< 45 years	1.00		
	> 45 years	3.06	(1.55, 6.03)	0.001
Gender	Female	1.00		
	Male	1.14	(0.53, 2.46)	0.731
Inconvenience caused by faecal incontinence	Low (0-2)	1.00		
	Median (3-6)	2.84	(1.22, 6.65)	0.016
	High (7-10)	2.98	(1.37, 6.48)	0.006
Self-assessed sufficiency of sexual counselling	Yes	1.00		
	No	3.07	(1.48, 6.35)	0.003

Hosmer & Lemeshow goodness of fit test: p=0.58 (Hosmer and Lemeshow 1989)

c) Model including age, gender, neuropathic pain, and self-assessed sufficiency of sexual counselling (n=179)

Predictor		OR	95 % CI	p
Age	< 45 years	1.00		
	> 45 years	2.56	(1.36, 4.83)	0.004
Gender	Female	1.00		
	Male	1.55	(0.74, 3.23)	0.247
Neuropathic pain	< 30 days	1.00		
	> 30 days	1.92	(1.01, 3.64)	0.046
Self-assessed sufficiency of sexual counselling	Yes	1.00		
	No	2.45	(1.22, 4.89)	0.012

Hosmer & Lemeshow goodness of fit test: p=0.56 (Hosmer and Lemeshow 1989)

### **MMC**

Fifty-nine percent of the men and 56 % of the women with MMC reported that they had received sufficient amount of sexual counselling. Those who reported the amount of sexual counselling as sufficient were more satisfied with their sexual life than the others (Mann-Whitney,  $p=.012$ ).

In the persons with MMC the median of self-assessed inconvenience caused by urinary incontinence was 4 (Q1=2, Q3=7) for the men and 4 (Q1=0.75, Q3=6.50) for the women. The median of self-assessed inconvenience caused by faecal incontinence was 3 (Q1=1, Q3=5) for the men and 2.5 (Q1=0, Q3=8) for the women. The self-assessed inconvenience caused by urinary or faecal incontinence did not affect sexual satisfaction in the persons with MMC (Spearman's rho  $-.08$ ,  $p=.612$ , and  $-.09$ ,  $p=.583$ , respectively).

Seven (17.5%) participants with MMC reported spasticity and only 3 (7.5%) reported that it affected their functioning. There was no association between spasticity and satisfaction with sexual life (Spearman's rho  $-.11$ ,  $p=.483$ ).

Seven (17.5 %) participants with MMC had a decubitus ulcer in at least one body area. Four men and one woman had a decubitus ulcer in the sacrum or buttocks, or at several locations. There was no association between decubitus ulcers and satisfaction with sexual life (Mann-Whitney,  $p=.323$ ).

The majority of the persons with MMC were single; only four men and seven women were married or co-habiting. Living with a stable partner seemed to increase sexual satisfaction in the whole group of participants with MMC (Mann-Whitney,  $p=.026$ ). This association was, however, based only on the results concerning the small group of men (Mann-Whitney,  $p=.041$ ). There was no association between marital status and satisfaction with sexual life in the women (Mann-Whitney,  $p=.963$ ).

In the final multivariable linear regression modelling age, gender, marital status, and self-assessed sufficiency of sexual counselling remained statistically significant predictors of satisfaction with sexual life (Table 12).

**Table 12.** Effects of age, gender, marital status, and self-assessed sufficiency of sexual counselling on satisfaction with sexual life in persons with MMC

Source of variation	F	p
Age	8.2	0.007
Gender	10.7	0.002
Marital status	6.3	0.017
Self-assessed sufficiency of sexual counselling	9.0	0.005



## **4.4 Paper IV**

### **4.4.1 Ergonomic evaluation**

The ergonomist's evaluation of the workplace focused mainly on problems related to accessibility and physical load factors associated with neck and shoulder disorders. Of the 7 participants, 4 had problems with accessibility, 2 had reaching problems, 2 had problems with workplace layout, 2 had problems with manual material handling, 1 participant had problems caused by static work, and 1 with body posture. In the self-evaluation by the VIDAR method the number of situations of concern reported by each participant ranged from 6 to 17.

Although the overall situation at work was evaluated, including arriving at the workplace, using the restroom and facilities for coffee and lunch breaks, the majority of improvements were implemented at each subject's personal workplace. The evaluation of work technique and workplace layout led, in five out of seven cases, to a remodelling of the workplace to get better access to items and tools. This way reaching far and nonneutral postures could be reduced. In three cases the working height was optimised by either replacing the chair or the desk with electrically controlled units allowing easy adjustment from time to time. Another example of an easily made improvement was the use of a headset while talking on the phone. In two cases a meeting with the employer and/or Swedish Social Insurance Agency was arranged.

### **4.4.2 Myofeedback training**

Five of the participants opted to take part in the myofeedback intervention. The experiences from these five users of the myofeedback device were mixed. The harness including the electrodes was difficult to don and doff for all but one and did not fit perfectly well those having an altered body posture caused by the SCL. Nevertheless, four participants completed the myofeedback intervention and two of the four reported at the follow-up interview that the device "provided information about how to reduce muscle tension in the neck/shoulder" and that keeping a diary about activities and pain was "instructive". The comparison of baseline and follow-up recordings of trapezius muscle activity during the computer-related tasks performed in the laboratory showed the RRT value, i.e. the same parameter that was evaluated and fed back to the user when insufficient rest was at hand during the actual intervention at the workplace, to increase in all four subjects taking part in the myofeedback intervention (Figure 10). This difference did not, however, reach statistical significance (paired samples t-test - 2.86,  $p=.064$ ).

**Figure 10.** Relative rest time (RRT) values from the four subjects participating in the myofeedback intervention. The presented bars show the RRT value as a mean value pooled for both sides and all three computer-related tasks, i.e. typing, precision task and the Stroop test, from each subject at baseline and follow-up.

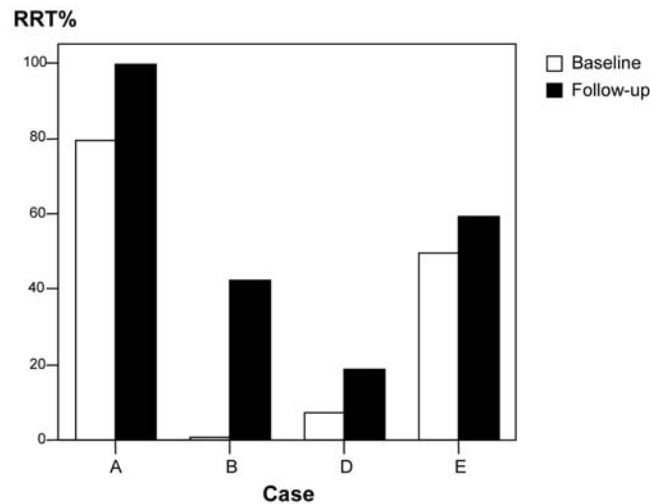


Table 13 summarises the ergonomist's evaluation before and after the intervention. The post-intervention assessment was made only in those cases in which changes had been made. As can be seen, situations of concern requiring action (assessed as "red" by the ergonomist) were markedly reduced.

Before the intervention, the median for neck and shoulder pain was 4 (25<sup>th</sup> percentile (Q1) was 2 and 75<sup>th</sup> percentile (Q3) was 7). After the intervention the median was 3 (Q1=0, Q3=6). This difference was statistically significant (Wilcoxon,  $p=.034$ ).

The results from the QPSNordic34+ showed only few changes with no apparent pattern in the psychosocial variables during the study period.

In the follow-up interviews a generally positive experience of the study was expressed and all subjects reported to have learnt ergonomic principles, which they applied actively in their work.

**Table 13.** Summary of the numbers of identified situations of concern for each subject. The ergonomist classified situations of concern (red or yellow) prior to ergonomic measures (pre). After changes the same situations were classified again (post).

Case	Ergonomist's evaluation*					
	Pre			Post		
	Red	Yellow	Green	Red	Yellow	Green
A	12	3	NA	3	5	7
B	2	2	NA	0	3	1
C	4	0	NA	2	2	0
D	5	4	NA	.	.	.
E	3	2	NA	1	4	0
F	0	4	NA	0	2	2
G	7	0	NA	.	.	.

\* Green: acceptable situation

Yellow: situation of concern requiring attention

Red: situation of concern requiring action

## **5. DISCUSSION**

### **5.1 Main findings**

A central finding in this thesis was that the work participation rate in Swedish SCL population is about two thirds of that in the healthy population (50% against 75%). Among the men with traumatic SCI, neuropathic pain and the presence of other somatic or mental disorders were associated with work participation, whereas most of these associations were not observed in the women with traumatic SCI or in the persons with MMC. The results of the workplace intervention study showed that the working conditions of persons with SCL can be improved by ergonomic measures. Satisfaction with sexual life was rather low in all subgroups except in the women with MMC. Medical problems associated with SCL, such as incontinence and neuropathic pain, affected satisfaction with sexual life in persons with traumatic SCI. In persons with MMC, none of the studied medical problems was associated with satisfaction with sexual life. The results also indicated that osteopenia and osteoporosis are more common among young adults with MMC than in the normative population. The effect of medical risk factors of osteoporosis on bone mineral density was modified by ambulatory status in this patient group.

New information on medical problems and participation in persons with SCL was obtained. Modifiable risk factors seem to play a major role in important parts of life. There are, however, some gender differences, as well as differences between persons with congenital and acquired SCL. Some discrepancies between the findings of this thesis and previous literature can be explained by demographic and cultural differences, adding practical relevance to this thesis.

#### **5.1.1 Osteoporosis in MMC (Paper I)**

Results of this study indicate that osteopenia and osteoporosis are more common among adults with MMC than in the normative population. Given the original hypothesis that this is mainly due to physical inactivity, it was somewhat surprising that there was only a trend for lower BMD at femoral neck among nonambulators compared with ambulators. On the contrary, the presence of other medical risk factors was an independent risk factor for lower BMD at femoral neck and trochanteric region of the hip. Furthermore, interactions between ambulatory status and medical risk factors indicated that the effects of medical risk factors were stronger among nonambulators than ambulators.

In previous studies among children with MMC, stronger associations have been found between ambulatory status and BMD (Quan et al. 1998, Rosenstein et al. 1987). Rosenstein et al (1987) found that both neurologic level of lesion and ambulatory status had a significant effect on bone density at the distal radius,

tibia, and first metatarsal in children with MMC (Rosenstein et al. 1987). In this study no significant correlation was found between the neurologic level of lesion and BMD. This suggests that the actual loading of the lower extremities is a predictor of BMD rather than the potential for ambulation in the form of neurologic level or motor score of the lower extremities.

The fact that no difference was seen in the BMD in the lumbar spine between the ambulators and nonambulators is in line with previous studies among subjects with traumatic SCI. It has been shown that there is a clear dissociation of BMD between the lumbar spine and the hip after an acute phase of paraplegia (Kannisto et al. 1998).

The results of this study suggest that besides low degree or lack of loading of the extremities, osteoporosis can be caused by neurogenic and metabolic mechanisms in this patient group. Lower BMD values in the forearm seen in some of the previous studies could be explained with such mechanisms (Quan et al. 1998). On the other hand, subjects with MMC load the upper extremities through the use of crutches or wheelchair, the effect of which could be an increase in BMD. In this study, bone density in the forearm was almost always within normative limits and only few patients showed osteopenia and none osteoporosis. In accordance with previous studies, in this study BMD tended to be lower in the forearm among the nonambulators than ambulators.

Previous studies have shown that subjects with bladder augmentation are prone to develop metabolic acidosis (Koch et al. 1992). Some studies have also shown that subjects with MMC may show hypercalciuria related to immobilization (Quan et al. 1998). In this study, all subjects showed normative standard bicarbonate and serum calcium values.

Previous studies in nondisabled subjects have shown that a low BMI is a risk factor for osteoporosis (Kanis 2002). In this study, however, there was no association between BMI and BMD. This is probably due to the fact that in subjects with MMC overweight is a common problem and most often a consequence of impairments in functioning (Fiore et al. 1998). In this study, those with higher BMI were more often nonambulators and the effect of BMI on BMD could therefore not be studied independently of ambulation. Moreover, the assessment of BMI can be unreliable in subjects with MMC due to altered proportions in body dimensions and eventual contractures in the lower extremities.

The prevention of fractures should be among the major goals in the rehabilitation of persons with MMC. The assessment of BMD is worthwhile in patients with risk factors for osteoporosis, because low BMD is a known risk factor for fractures (Kanis 2002). The fact that no association was found between

BMD and history of fractures was probably due to the small sample size and the retrospective nature of the information concerning fractures.

### **5.1.2 Work participation in SCL (Paper II)**

The overall employment rate in this study was 47% among persons with traumatic SCI and 40% among persons with MMC. The results are in line with those from a previous Swedish study by Levi et al (1996). They reported that 46% of their study population, consisting of persons with SCI living in Greater Stockholm area in Sweden, were gainfully employed. These figures are clearly lower than the overall employment rate of 73% in the general Swedish population aged 15 to 64 in 2003 (Eurostat 2004). On the other hand, the vocational outcome seems to be somewhat more optimistic than, for example, in the US where less than 30% of the 18- to 62-year-old persons with traumatic SCI were gainfully employed, or in the UK where only 26% of the persons with meningomyelocoele aged 27 to 33 were in open employment (Hunt et al. 1999, Krause et al. 1999). The wide variation in employment rates between different countries can at least partly be explained by differences in social support and insurance systems. However, differences in the length of rehabilitation, as well as differences in people's attitudes to persons with functional impairments may also play a role.

Despite the fact that MMC is a congenital SCL, rehabilitation outcomes are seldom compared with those with traumatic SCI. In Göteborg, Sweden, persons with traumatic SCI and persons with MMC are rehabilitated at different departments of Sahlgrenska University Hospital. The lack of difference in work participation rates between these two groups suggests that existing resources and possibilities are effectively used at both departments. One could argue that the relatively high employment rate in the MMC group is artificial since the proportion of those whose employer received wage supplement from the government was higher in the MMC group than in the traumatic SCI group. It should be emphasised that to have this kind of support as a disabled person, one has to find a way to the labour market by attracting an employer. Furthermore, this kind of support covers only part of the employment costs and is time-limited. Therefore this support is different from sheltered work.

Men and women with traumatic SCI seemed to differ from each other also regarding the predictors of work participation. Age, age at injury, and neuropathic pain, for example, did not seem to affect work participation in the women with traumatic SCI. We do not know whether neuropathic pain not being a predictor is due to higher tolerance or better coping strategies among the women or something else. Previous studies have shown that coping strategies differ between men and women, women using emotion-focused coping more

frequently than men (Renk and Creasey 2003). However, the results of this study emphasise the importance of maintaining genus perspective in SCL rehabilitation and research.

The fact that neurological level or ambulatory status did not affect work participation in the subjects with traumatic SCI was somewhat surprising. A more detailed assessment of the degree of neurological impairment might have provided additional information, but was not available in our study. Among the persons with MMC use of a wheelchair for ambulation increased the risk of non-participation in work. In this patient group ambulatory status may more reflect the overall functional and cognitive capacity than in the traumatic SCI group. On the other hand, higher functional independence, assessed by the Self-reported Functional Measure, predicted work participation in all subgroups. It is encouraging that in the traumatic SCI group the persons with limited ambulatory capacity seemed to have equal opportunities to participate in work. It is therefore worth-while to rehabilitate these persons vocationally despite the neurological level of the injury. However, independence in daily activities is a factor that should be taken into consideration when considering possibilities of vocational rehabilitation. Based on the results of our study Self-reported Functional Measure seems to be a useful tool in assessing vocational capacity of a person with SCL.

Previous studies in persons with traumatic SCI and MMC have shown that problems with bladder and bowel function are associated with work participation and quality of life (Hicken et al. 2001, Lonton et al. 1983, Stiens et al. 1997, Tew et al. 1990). Therefore, our results showing no association between urinary or faecal incontinence and work participation in any of the subgroups were unexpected. One explanation could be the duration of rehabilitation in Sweden, which is much longer than for example in the US (Eastwood et al. 1999). During a longer rehabilitation period a person has more time to learn how to cope with the problem in everyday life. Improved incontinence aids could be another explanation for the differences in the results between our study and previous studies.

Mental disorders, as well as alcohol and narcotic abuse are problems seen also among persons with traumatic SCI (Johnson et al. 1998, Levi et al. 1995). These disorders have rarely been taken into consideration in studies on vocational outcome. The results of this study showed that the presence of mental disorder is a strong risk factor for non-participation in work. There is a need for collaboration between specialists in the rehabilitation of SCL and specialists in psychiatric rehabilitation. The fact that no association was found between narcotic abuse and work participation may be due to selective non-response, i.e. the abusers replying less frequently to our questionnaire than the others, or denial of abuse by the respondents.

The association between the level of education and work participation in the traumatic SCI group was not as strong as previously reported (Anderson and Vogel 2002, Krause et al. 1999). This might be due to the relatively complex classification system of different educational levels in Sweden. Furthermore, the educational system has changed to some extent during the last decades. On the other hand, in the MMC group, higher level of education was clearly associated with better vocational outcome. It was also quite encouraging to find out that vocational rehabilitation improved work participation at least in the men with traumatic SCI.

In our study 6% of persons with traumatic SCI and 8% of persons with MMC reported that they had been bullied at work. These numbers are at the same level as those in the normal Swedish population. According to the Work Environment Survey carried out by Statistics Sweden in 2001 9% of men and 9% of women had been bullied by supervisors or fellow employees (Arbetsmiljöverket 1999).

Nearly 80% in both patient groups rated satisfaction with their current work situation as very good or rather good. This is at the same level as in the general Swedish population, in which the corresponding proportion has been about 75% (Torgén et al. 2001). The similarity in the level of satisfaction in different life domains between persons with MMC and an average population is in line with previous studies (Andren and Grimby 2004). The results of this study support the previous findings according to which work participation is associated with better quality of life in persons with SCI (Anderson and Vogel 2002, Leduc and Lepage 2002). However, the cross-sectional design of this study does not allow conclusions regarding causality.

Gainful employment is usually considered as one of the most important goals of rehabilitation. Considering the difference between employment rates in the general population and persons with SCL, one can say that there is still space for improvement. On the other hand, gainful employment is not the only goal for rehabilitation. Independence in daily activities and quality of life are other important aspects in rehabilitation. Therefore, it is a matter of taste, if work participation rate of two thirds in persons with severe functional impairments of that in the healthy population (about 50% against 75%) is considered as if the goal has been reached. However, active rehabilitation and continuous support of persons with SCL towards work participation is worth-while, since employment may improve quality of life.



### 5.1.3 Satisfaction with sexual life in SCL (Paper III)

The main findings in this study were that satisfaction with sexual life was rather low among persons with traumatic SCI. The men with MMC also showed a low rating of sexual satisfaction, whereas the women with MMC were fairly satisfied with their sexual life, which is a finding not reported earlier. Sexual satisfaction declined with age in the men with traumatic SCI and among the persons with MMC. Somewhat surprisingly, this effect of age was not seen in the women with traumatic SCI. Self-assessed inconvenience caused by urinary or faecal incontinence increased the risk of sexual dissatisfaction in the persons with traumatic SCI but not in the persons with MMC. Neuropathic pain increased the risk of sexual dissatisfaction in the men with traumatic SCI but not in the women. Among the MMC group those who were married or co-habiting showed higher satisfaction with sexual life than those living without a partner. Sixty-nine percent of the men with traumatic SCI and 56-59% of the participants in other subgroups reported that the sexual counselling they had received was sufficient. In all subgroups those who considered the sexual counselling they had received as sufficient were more satisfied with their sexual life than the others. Since our study was cross-sectional it does not, however, provide evidence for causality.

The results of this study corroborate findings from earlier studies that satisfaction with sexual life is rather low among persons with traumatic SCI (Benevento and Sipski 2002, Kreuter et al. 1996). They are also in line with previous findings that age at injury affects sexual adjustment (Siösteen et al. 1990a). In this study especially ageing men with traumatic SCI who had sustained their injury at an older age were most dissatisfied with their sexual life. It is a challenge for rehabilitation to help these men to adjust themselves to a new situation.

Preliminary analyses suggested that there would be no association between the neurological level of the injury and satisfaction with sexual life, which is in line with previous studies (Kreuter et al. 1996, Siösteen et al. 1990a, Westgren et al. 1997). However, when the men and women were analysed separately, a gender difference was found. The men with cervical injuries were more satisfied with their sexual life than the men with lower injuries, whereas in the women the situation was the opposite. When considering the effects of SCL on sexual functioning, i.e. more frequent erections in men with upper motor neuron lesions than in men with lower motor neuron lesions, and knowing the fact that physical sexuality seems to be more important for men, this gender difference is not unexpected (Baldwin and Baldwin 1997, Burns et al. 2001). Lower injuries being associated with higher satisfaction with sexual life in women may be due to a larger body area with normal sensitivity.

Urinary and faecal incontinence, as well as neuropathic pain, are problems related to SCL (Levi et al. 1995, Sadowsky et al. 2002). It is well known that these problems can affect quality of life in many ways (Haythornwhite and Benrud-Larsson 2000, Hicken et al. 2001). Based on the results of this study they are also associated with sexual satisfaction. Adequate treatment of these medical problems might improve even sexual satisfaction among persons with SCL. Although in previous studies spasticity has been reported as one of the major concerns as regards sexual life, we did not find any association between spasticity and satisfaction with sexual life (Jackson and Wadley 1990, Westgren et al. 1997). It was also somewhat surprising that the presence of decubitus ulcers did not affect sexual satisfaction, since decubitus ulcers are known to affect functioning and quality of life (Langemo et al. 2000). The lack of association may be due to a small number of persons with decubitus ulcers.

Fairly little is known about sexual satisfaction in persons with MMC. Previous studies have mainly focused on sexual functioning (de Vylder et al. 2004, Sandler et al. 1996, Tünte 1971, Verhoef et al. 2004). In a previous study carried out in young adults with MMC, half of the patients were satisfied with their present sex lives (Verhoef et al. 2004). In a study carried out by Sawyer and Roberts (1999), persons with MMC reported concerns of urinary incontinence interfering their sexual life. In the light of this result, it is somewhat surprising that in our study none of the medical conditions showed association with satisfaction with sexual life among persons with MMC (Sawyer and Roberts 1999). On the other hand, persons with MMC have lived with their injury since birth, and may have learned to cope with the problems related to it better than persons with acquired SCL.

Even though we did not test for differences between the traumatic SCI and MMC groups, it seems as the persons with MMC were more satisfied with their sexual life than the persons with traumatic SCI. This was, however, mainly based on the high satisfaction with sexual life in women with MMC. This is likely due to the fact that the function of the sexual organs is relatively little affected in women with MMC (de Vylder et al. 2004). It may also be due to different interpretations of intimacy between men and women, i.e. the women appreciating more activities reflecting romanticism (Purnine et al. 1994). On the other hand, there was no gender difference among persons with traumatic SCI. In fact, the women with MMC and the women with traumatic SCI showed a remarkably different level of sexual satisfaction. The women with MMC were in the upper end of the scale, whereas the women with traumatic SCI were in the lower end of the scale. This difference between these two groups may be explained by the fact that the latter compare their sexual life in the current situation with what they had before they were injured.

Four women with MMC had given birth to six children (one child with MMC) but none of the men with MMC had children. This raises a question about inadequate knowledge about the new possibilities to treat infertility in the men with MMC (Dahlberg et al. 1995). However, it must be kept in mind that there were only four men with MMC living in a stable relationship in our study population.

Considering the huge effect SCL has on sexual function, sexual counselling is very important for the person with SCL and the partner. This is regularly offered to newly injured as well as persons who have lived with their injury for a long time. It is encouraging that, depending on the subgroup, 56-69% of the participants reported that the amount of sexual counselling had been sufficient. For those who assessed the counselling as insufficient, it may be because the person had not received counselling or because loss in sexual functioning is frustrating and not amendable by sexual counselling. The self-assessed sufficiency of sexual counselling was slightly lower among the women compared with the men, which might be due to the fact that women do not have the same obvious reason for seeking help and because fertility in women remains unaffected after a spinal cord injury (Benevento and Sipski 2002). Moreover, women form a minor group among persons with SCL and may have drawn less attention than men (Jackson and Wadley 1999, Westgren et al. 1997). Sexual counselling should be given to all individuals with SCL and to their partners. Sexual counselling for the individuals with MMC is a special challenge, which has to be remembered during teenage and young adulthood as an important part of the rehabilitation process. Proper management of concurrent medical problems has to be considered in sexual rehabilitation of persons with SCL.

#### **5.1.4 Ergonomic intervention (Paper IV)**

This study suggests that it is possible to evaluate the working conditions of persons with SCL with quite similar methods as in the normative population. The evaluation process should, however, be extended from a person's personal workplace to also include arriving at the workplace, using the restroom, and facilities for coffee and lunch breaks. The results of our study also showed that the working conditions of persons with SCL can be improved with small and easily performed changes, such as reorganisation of furniture, assessment of working techniques, and changes in the of table or work chair.

The need for workplace accommodations to enhance return to work after SCL is well recognised in the literature (Inge et al. 1998). The extent to which ergonomic aspects at workplaces are discussed at follow-up visits may vary in different rehabilitation units. Based to my clinical experience, persons with SCL rarely spontaneously bring up the problems with working conditions. One

explanation is that when coming back to working life after rehabilitation, the focus is to be a person with some disabilities, rather than a disabled person. Thus, extraordinary actions and special treatments are not welcomed, with the possible consequence of also missing out on aids, actions and advice from a user-centred perspective, i.e. useful to all employees. Persons with SCL may also relate the problems with working conditions to their functional impairment and therefore assume that these problems cannot be helped.

The myofeedback method based on the approach of promoting muscle rest by means of RRT evaluation of the trapezius muscle is a novel part of the intervention. The result of increased RRT values in all participants who completed the myofeedback intervention is very promising. However, it must be kept in mind that not only the myofeedback intervention may have contributed to the increased amount of muscle rest seen between baseline and follow-up but also the changes carried out at the workplace and advice on work technique.

This study shows that the intervention program performed led to improvements in working conditions. This was supported by the interviews where a generally positive experience of the study was expressed and all subjects reported using the ergonomic information communicated by the study. However, such reports can be expected just from the fact that the subjects got attention in connection with the workplace intervention.

This study shows that it seems in practice feasible to implement ergonomic changes at the workplace of a disabled person. These changes seem to reduce situations of concern in an assessment by an ergonomist. The results also suggest that this type of intervention may decrease neck and shoulder problems in persons with SCL. However, more studies with larger sample size, a control group, and longer follow-up time are needed to establish this finding.

## **5.2 Methodological aspects**

### **5.2.1 Study population and participation rates**

One of the weaknesses of the studies in this thesis was the relatively low response rate, which may be due to an extensive questionnaire. In the questionnaire studies of this thesis, the response rate was 50-60%, depending on the subgroup. This naturally sets limitations to generalisability of the results. Yet, in persons with MMC an overall response rate of 60 % and higher than 50 % regarding the questions of sexual life can be considered as satisfactory, since persons with MMC are a difficult group to approach with a scientific study (Sawyer and Roberts 1999). Since the same predictors were used in different

studies, we decided to send out one extensive questionnaire instead of 2-3 smaller ones. This choice probably affected the response rates.

Although our analyses showed that our study groups were well representative of the total study populations with regard to gender and neurological level, there are sources of potential bias. There is a possibility that those with better functional capacity and better vocational outcome responded more often than those with more severe functional impairments or the unemployed. This would mean that the true employment rate among persons with SCL would be somewhat lower than what our results suggest. Our analyses showed that those who replied were somewhat older than the non-respondents. This, and the finding of sexual satisfaction declining with age in previous studies and this study suggest, that satisfaction with sexual life might be somewhat higher than results of this study indicate (Black et al. 1998, Kreuter et al. 1996, Siösteen et al. 1990).

In the questionnaire studies the medical files of the respondents or non-respondents were not available to verify variables such as work situation and medical problems. Even if we had checked these variables in the medical files a lot of data would still have been missing or be unreliable because some of the patients had moved to an other area and some other had dropped out from the annual check-ups in the clinic. It can be assumed that this is especially true for those who did not respond to the questionnaire.

In the osteoporosis study the study population was fairly small so that few results could be ascertained with statistical significance. The low participation rate could be due to the fact that persons with MMC already have numerous contacts with various health professionals. Some of them might not want to know whether they have osteoporosis, and that can be seen as one of their coping strategies. One could also claim that the amount of functional impairments and the prevalence of other comorbidities were higher among the nonparticipants than among the participants. If so, the BMD may be even lower in MMC than the results of this study suggest. However, the study population was very well representative of the source population with regard to age, sex, and ambulatory status. Therefore the results have generalisability with regard to other Young Adult Team patient populations.

### **5.2.2 Study design**

As explained earlier in the discussion of the results, the cross-sectional design of this study does not provide any information of causality. We had, however, insufficient resources to carry out a longitudinal study.

There were no healthy controls in this thesis, although they would have enriched the study on sexual satisfaction. On the other hand, population statistics on work participation rates are readily available. Moreover, the main aim was to study effects of different injury-related variables on satisfaction with sexual life and work participation, which does not require the use of healthy controls.

It is well known how difficult it is to study sexual issues (Durant and Carey 2000). Some prefer interview but when dealing with intimate questions a questionnaire might give more reliable answers and also diminish the bias caused by subject selection (Durant and Carey 2000). The fact that we were limited to self-reported data indicates the need for caution in interpreting the results especially as regards the medical characteristics.

### **5.2.3 Assessment of the outcomes and the risk factors**

Even though there are certain problems using DXA to determine BMD in persons with MMC, it is thus far the golden standard method to assess BMD. The decision to use North-American reference population offered by the manufacturer may have caused overestimation of the prevalence of osteoporosis in the hip, since a study carried out by Löfman et al (1997) showed that normal values for femoral neck BMD in Swedish women prior to menopause are significantly lower than the manufacturer's normal values. No such difference in premenopausal women was found for lumbar spine BMD values (Löfman et al. 1997).

We could not find reliability and validity tested instruments to study satisfaction with sexual life appropriate for our purposes mainly because we had two different patient groups (traumatic SCI and MMC). Since there was lack of standardized questionnaires for sexual satisfaction suitable for this study, we decided to use a numerical scale from 0 to 10 (i.e. an ordinal VAS-scale), which is a well known, simple and widely used assessment method in different study areas (Bijur et al. 2001, Capodaglio 2001, Gupta et al. 2000, Lukacz et al. 2004). No further psychometric development or validation was done. One of the weaknesses of the study on satisfaction with sexual life was that there were only few questions about sexual life and no question about sexual activity. However, it must be kept in mind that a person can be satisfied with his or her sexual life even if we think that the traditional elements of sex are absent (Halstead et al. 1978, McCabe and Taleporos 2003). Furthermore, by increasing the amount of questions on sexual life, the response rate would probably have been even lower.

Work participation was assessed with a question previously used in a study by Torgén et al. (2001). Since the number of full-time students was insufficient (n=6 in the traumatic SCI group and n=10 in the meningomyelocele group) to keep them as separate groups in logistic regression modelling, they were

included in those participating in work, assuming that full-time studies lead to work participation. This reasoning can be criticised since it is well known that all studies do not necessarily lead to work participation.

## 6. CONCLUSIONS

- Osteoporosis is a medical problem that must be considered when treating and rehabilitating persons with MMC.
- Our results indicate significant modification of hypothesised associations between ambulatory status and BMD by other medical risk factors, an interaction that has potential clinical implications for the identification of high-risk individuals.
- Work participation rate in Swedish SCL population is about two thirds of that in the healthy population (about 50% against 75%).
- Independence in daily activities is a factor that should be taken into consideration when assessing possibilities of vocational rehabilitation. Self-reported Functional Measure may be a useful tool for assessing vocational capacity of persons with SCL.
- Active rehabilitation and continuous support of persons with SCL towards work participation is worth-while, since employment may improve quality of life.
- The working conditions of the persons with SCL can be improved by ergonomic measures.
- Satisfaction with sexual life is rather low among persons with SCL. The high satisfaction with sexual life in the women in comparison with the men with MMC is a finding not reported earlier.
- Adequate treatment of incontinence and pain might improve even sexual satisfaction.
- Sexual counselling should be given to all individuals with SCL and to their partners. Sexual counselling for young adults with MMC is an important part of the rehabilitation process.
- Especially ageing men with traumatic SCI who have sustained injury at an older age are a challenge for rehabilitation.



## **7. NEEDS FOR FURTHER RESEARCH**

More studies, especially longitudinal studies, are needed to learn about the prognosis of osteopenia and osteoporosis in subjects with MMC and about the effects of different treatment regimens.

More research is needed about factors affecting work satisfaction in SCL, and longitudinal studies are needed to learn more about association between work participation, and quality of life in SCL.

The reasons behind low motivation as an obstacle for work participation in SCL should be studied more in depth, perhaps using qualitative approaches.

More research, both qualitative and quantitative, is needed about sexual behaviour in persons with MMC.

Prospective, multi-centre studies are needed to assess fertility and pregnancy in women with SCL.

Studies with larger samples are needed to assess the effects of workplace interventions on neck and shoulder problems in persons with SCL.

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