



## Medical complication in adults with spina bifida

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### ABSTRACT

**Setting:** Cohort study.

**Introduction:** Spina bifida (SB) is a congenital malformation affecting the central nervous system (CNS) and is one of the most prevalent CNS disorders in children. Hydrocephalus (HC) is present in 80% of newborns with SB. The aim of the present study was to analyze the medical complications and to relate the complications to age at examination, the level of injury, AIS grade and presence of HC in adults with SB.

**Materials and methods:** SB patients were recruited from the Spinalis out-patient clinic at the Karolinska University Hospital at their annual follow-up. The patients underwent a thorough general and neurological examination and background data including medical complications were retrieved from the medical files.

**Results:** 127 of 157 (82%) SB patients (114 with MMC and 13 SB occulta) with a mean age of 34 years were included. Half of the patients had a complete SCI and a lumbar level was most common. Nearly 60% of the patients had HC. 88 patients (69%) suffered from at least one medical complication. Urinary tract infection (UTI), scoliosis and pain were the most common complications found in 46%, 30% and 28% of the patients, respectively. Less common complications were epilepsy, pressure ulcers (PU) and spasticity.

**Discussion:** SB gives a disability including motor, sensory dysfunctions and the patients suffer from a high frequency of medical complications like UTI, scoliosis, pain, and epilepsy. Data gives basis for adequate routines for medical examination at the follow-up.

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### 1. Introduction

Spina bifida (SB) is one of the most prevalent central nervous system (CNS) disorders in children. SB is an early congenital malformation affecting CNS and occurring within the first 6 weeks of pregnancy, possibly caused by a combination of genetic and environmental factors. The rate of SB among newborns has gradually diminished [1,2] and today 20–25 children/year are born with SB [3] in Sweden.

The most common site of SB is the lumbo-sacral region. Occasionally it is found in the thoracic region and very rarely in the cervical region [5]. In the area of the spinal defect the spinal cord is damaged [3,4]. There are mainly three forms of SB (1) spina bifida occulta, (2) meningocele and (3) myelomeningocele (MMC). Spina bifida occulta being the less serious form of SB. MMC is the most disabling form of SB [6]. In several cases the patients suffer from mental retardation. In the clinical daily practice when speaking about SB we usually mean MMC. In addition, approximately 80% of

the new-born with SB suffer from hydrocephalus (HC) which more often is congenital but may develop during the first week of life. In the developed part of the world most patients with SB survive childhood and become adults which bring new challenges for caregivers and the social welfare systems often due to several medical complications. Treatment of HC is a shunt operation, during the first period of life. Complications occur mostly during the first years of life but can occur during all periods of life. It is therefore important to react when neurological symptoms occur in patients with HC.

Neurogenic bladder dysfunction may cause incontinence, retention of urine, urinary tract infections (UTI) and as a consequence, if not treated adequately, may lead to renal failure.

Scoliosis may cause severe respiratory problems and surgical intervention may be needed.

Pressure ulcer (PU) may occur in all periods of life and treatment might require surgery and a long rehabilitation period.

Furthermore, a higher prevalence than in the normal population of disorders such as diabetes mellitus and hypertension has been reported in SB and some of the individuals with SB suffer from epilepsy, due to brain damage.

The present study was performed in order to evaluate the prevalence of different medical complications in a SB cohort in order to

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increase the knowledge of the medical situation for adults with SB. This is in order to develop adequate routines for medical examination and follow-up of SB patients in the out-patient clinic. The medical complications were compared with the neurological level, completeness of injury, presence of HC, age at the time of examination and gender in order to identify sub-groups with need of special attention.

## 2. Materials and methods

All adult patients with SB in the greater Stockholm region who underwent a yearly follow-up at the Spinalis out-patient clinic during 1 year were included in the study. Data were retrieved from the computerized medical files at the Spinal out-patient clinic. The Spinalis out-patient clinic at the Karolinska University Hospital, Stockholm, Sweden is an out-patient clinic for non-traumatic and traumatic spinal cord injuries (SCI) and for adults (over the 18 years) with SB in the greater Stockholm area. Furthermore, the medical records from the primary care centers and from the pediatric, orthopedic and neurosurgical departments were studied in order to evaluate if the patients had undergone surgery and if they have had severe diseases in the past. The patients with SB were divided in SB occulta and MMC.

At the yearly follow-up, patients were examined by an experienced physician, one of the authors (LW). The examining physician interviewed the patients according to a specific questionnaire with special attention on their medical history including other diseases and surgical interventions in the past as well as bladder function, the frequency of UTI during the last year. Bladder emptying was divided in (1) normal emptying, (2) intermittent catheterization, (3) indwelling catheter and (4) urostomy. The presence of epilepsy and pain and its character were recorded.

The neurological examination included evaluation of tendon reflexes and sensory and motor functions. Sensory testing included light touch with a cotton swab and pin-prick with a needle. In selected cases sensibility for warm and cold were tested. For evaluation of motor function motor index (0–100) were used. The patients were classified according to AIS (American Spinal Injury Association Impairment Scale) (A–E) and to the neurological level [7].

The neurological level was defined as the lowest level with normal motor and sensory functions.

The general examination included measuring of blood pressure in a supine position, evaluation of the heart and lung functions, inspection of the skin in order to detect PU or signs of earlier PU. An examination of the muscle and skeletal system was performed.

At the examination blood samples were taken including serum glucose, cholesterol and triglycerides.

## 3. Definitions of medical complications

*UTI* was defined as an infection of one or more structures in the urinary system with symptoms like fever, increased spasticity etc. We did however not study if the patients received treatment or not for their UTI.

*PU* was graded in the four grades 1–4 according to the National Pressure Ulcer Advisory Panel' updated pressure ulcer staging system (NPUAP) [8].

*Pain* neuropathic pain (NP) was defined as a pain occurring in an area with decreased sensibility and without relations to movements or inflammatory signs [9] and nociceptive pain was defined as an aching pain in an area with signs of inflammation and painful joint movements.

*Spasticity* was defined as increased muscle tone (and an increase in the deep tendon reflexes). The Ashworth scale (0–4) was used to measure spasticity [10].

**Table 1**

Description of adults with myelomeningocele (MMC)  $n = 114$  and spina bifida (SB) occulta  $n = 13$  in the greater Stockholm area regarding gender, neurological level, AIS (see description in the text) and occurrence of hydrocephalus (HC).

Variables	MMC, $n = 114$	SB occulta, $n = 13$	Total, $n = 127$
Gender			
Female	58 (51%)	8 (62%)	66 (52%)
Male	56 (49%)	5 (38%)	61 (48%)
Neurological level			
Th 1–8	5 (4%)	0	5 (4%)
Th 9–12	23 (20%)	0	23 (18%)
L 1–5	78 (68%)	5 (38%)	83 (65%)
AIS			
A	56 (49%)	0	56 (44%)
B–C	27 (24%)	0	27 (21%)
D	23 (20%)	5 (38%)	28 (22%)
E	3 (3%)	8 (62%)	11 (9%)
Hydrocephalus			
Yes	70 (62%)	0	70 (55%)
No	44 (38%)	13 (100%)	57 (45%)
NT (non testable)	5 (4%)	0	5 (4%)

NT means not tested according to the AIS classification.

*Diabetes mellitus* was present when a fasting blood glucose over 6,0 mmol/l was identified and/or when the patient was under medication.

*Hypertension* was defined according to the standards at the Karolinska University Hospital present when the blood pressure was over 135/85 and/or when the patient was under antihypertensive medication.

### 3.1. Analysis of data

Groups and sub-groups are presented as absolute numbers and percentages. Comparisons between groups were made by  $\chi^2$ -tests or by Fischer' exact test when the numbers were too small to allow  $\chi^2$ -test.  $p < 0.05$  were considered significant.

### 3.2. Ethics

The study was approved by the Stockholm Regional Ethical committee.

## 4. Results

In the database at the Spinalis out-patient clinic 157 patients with the diagnosis of SB were identified. 25 patients did not answer our letter or did not want to participate. After examination 5 patients did not fulfill the diagnostic criteria for SB and were excluded.

Finally, 127 patients with the diagnosis of SB were included in the study. Of 127 patients 114 suffered from MMC the most severe form of SB: for a presentation of the included patients regarding gender, age at the time of examination, presence of HC, AIS, the neurological level see Table 1.

As seen in Table 2 HC was more often present in patients with a thoracic neurological level and in patients with a complete SCI. The medical records from the pediatric and neurosurgical departments revealed that all patients with HC underwent surgery early in life. Younger patients more often had a complete injury and HC (Table 3).

The percentage of medical complications appears in Table 4. UTI was the most common medical complication occurring in 58 of the 127 patients (48%). Patients with a complete SCI (AIS A) had more often UTI than patients with an incomplete SCI, a difference that reached statistical significance ( $\chi^2 = 7.006$ ,  $p = 0.0081$ ). However, there was no statistically significant difference between UTI in patients with or without hydrocephalus ( $\chi^2 = 3.485$ ,  $p = 0.0619$ ). Of

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