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Voiding conditions, renal and bowel function in a cohort of adults with spina bifida

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Abstract

Aim: To map voiding patterns, degree of continence, use of drugs for voiding disorders, kidney function and surgical interventions but also the bowel function in a near-total regional cohort of adults with spina bifida aged more than or equal to 18 years.

Methods: All individuals more than or equal to 18 years of age with spina bifida registered at a regional outpatient clinic (n = 219) were invited to participate, of which 196 persons were included. Bladder and bowel function were assessed according to questions used by the Nordic Spinal Cord Injury Registry by structured interviews and questionnaires in combination with review of patient charts including kidney function.

Results: Twenty percent of the patients voided spontaneously. Fifty-four percent used clean intermittent catherization (CIC) and of these, 14% had also undergone augmentation of the bladder and/or implantation of an artificial sphincter or sling, 23% had undergone major urological surgery, and 3% had an indwelling catheter. Seventeen percent of patients voiding spontaneously or using CIC reported total continence but as many as 36% reported daily leakage. Anticholinergics was the most common drug, used by 21% in the total cohort. About 13% of the patients had a reduced kidney function but only 1.5% had end stage renal failure. Seventy-three percent had problems emptying the bowel and 18% experienced fecal leakage weekly or even daily.

Conclusion: We found a large variation in problems with bladder and bowel function in this adult group of persons with spina bifida. A structured customized program for follow-up seems necessary to optimize their health status in these areas.

KEYWORDS

constipation, fecal leakage, neurogenic bladder dysfunction, renal dysfunction, urinary incontinence

1 | INTRODUCTION

Spina bifida (SB) is a congenital neuroembryological disorder affecting multiple organ systems, and in most cases, there is a neurogenic dysfunction in both the urinary tract and the bowel.[1] The majority of persons with SB experience neurogenic bladder dysfunction with voiding difficulties, with or without involuntary leakage, recurrent urinary tract infections (UTIs), and increased risk for renal deterioration.[2] Also, dysfunction of the bowel causing constipation and/or fecal incontinence is a common problem in this patient group.[3]

The incidence of SB has decreased over the last decades and in Sweden the annual incidence of SB is estimated to 10 to 20 per 100 000 newborns/year.[4] Previously, the literature focused mainly on children and young adults with SB (≤25 years) and their transition to adulthood.[5-7] Today, most persons with SB reach adulthood, thanks to the development of better medical treatments and there is a need to broaden the focus to include all adults with SB in a life-long perspective.[2] The aim of this study was to map the voiding patterns, degree of continence, use of drugs for voiding disorders, kidney function, and surgical interventions but also the bowel function in a near-total regional cohort of adults with SB aged more than or equal to 18 years.

2 | PATIENTS AND METHODS

At the Spinalis Outpatient Clinic at Rehab Station in Stockholm a cross-sectional study of a near-total regional cohort of adults with SB within the Greater Stockholm area was conducted by a multidisciplinary team.[8]

The Spinalis clinic is responsible for health care follow-up for all adults with SB in the Greater Stockholm area. All adult persons, 18 years and older, registered with SB (n = 219) were invited to participate in the study; 196 (89%) were included; 19 declined, and four did not respond. As part of the study, we investigated the voiding conditions, renal function, and bowel function in the cohort. Bladder and bowel function were assessed according to questions used by the Nordic Spinal Cord Injury Registry (NSCIR)[9] in structured interviews and questionnaires in combination with review of patient charts. The NSCIR is not validated for this population but was used due to similarities in bladder and bowel dysfunction since validated questionnaires for persons with SB is under way but not yet finalized.

Participants were informed about the study verbally and in writing and gave their signed informed consent to participate. In a few cases with intellectual disability, the written consent was given by the participant's personal assistant. Due to cognitive impairment, less than 10 of the participants had help from their assistance providers to answer the questions, in some cases mainly for confirmation and in some cases with a major part of the questions.

TABLE 1 Age distributions of the participants

	Females	Males
Group 1: 18-30 y	42	48
Group 2: 31-45 y	28	32
Group 3: 46-60 y	28	10
Group 4: 61- y	6	2

3 | RESULTS

The 196 participants had a mean age of 35 years (range18-73), 104 females with a mean age of 37 and 92 males with a mean age of 33 years, with a higher proportion of females in the older age groups, see Table 1. A majority (179 participants, 91%) were diagnosed to have a myelomeningocele (MMC), (35 thoracic-, 1 thoracolumbar-, 114 lumbar-, 8 lumbosacral- and 21 sacral level). Fourteen patients had a diagnosis of lipomeningocele (1 thoracic, 6 lumbar, 3 lumbosacral, and 4 sacral) and three in the cohort were diagnosed with SB occulta. One hundred and twenty-three of the patients (63%) had hydrocephalus.

Forty patients (20%) voided spontaneously, a fourth of them with strain. In this group more than 50% of the patients with lipomeningocele or spina bifida occulta was found. Since these persons can be expected to be less affected, the results for this subgroup is also reported separately at the end of the results section. Clean intermittent catherization (CIC) was used by 105 (54%) of the patients and of these, 16 (14%) had also undergone augmentation of the bladder and/or implantation of an artificial sphincter or sling (Figure 1). Six participants (3%) had an indwelling catheter.

Forty-five (23%) of the patients in the total cohort had undergone major urological surgery; 11 had a vesicostomy with or without bladder augmentation, 19 had a continent urinary diversion, and 15 had an ileal conduit. Ileal conduit is by far the most common type of major surgery in the older age groups, a continent reservoir is common in all but the oldest group and vesicostomy with or without bladder augmentation is now performed in many of the patients, as seen in the two youngest age groups (Figure 2A). About 69% of the patients who had undergone major surgery were female and as many as 11 of the 15 patients who had an ileal conduit were female (Figure 2B).

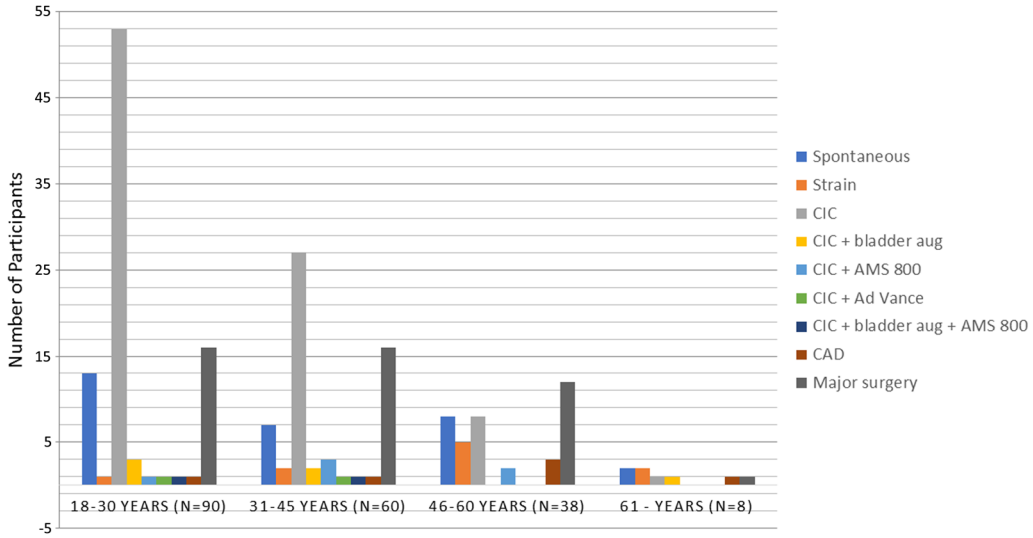

FIGURE 1 Type of voiding in the different age groups. Spontaneous, strain, clean intermittent catherization (CIC), CIC after bladder augmentation, CIC after implantation with artificial sphincter (AMS 800), CIC after surgery with artificial sling (Ad Vance), CIC in combination with bladder augmentation and implantation with artificial sphincter (AMS 800), indwelling catheter (CAD), major urological surgery specified in Figure 2

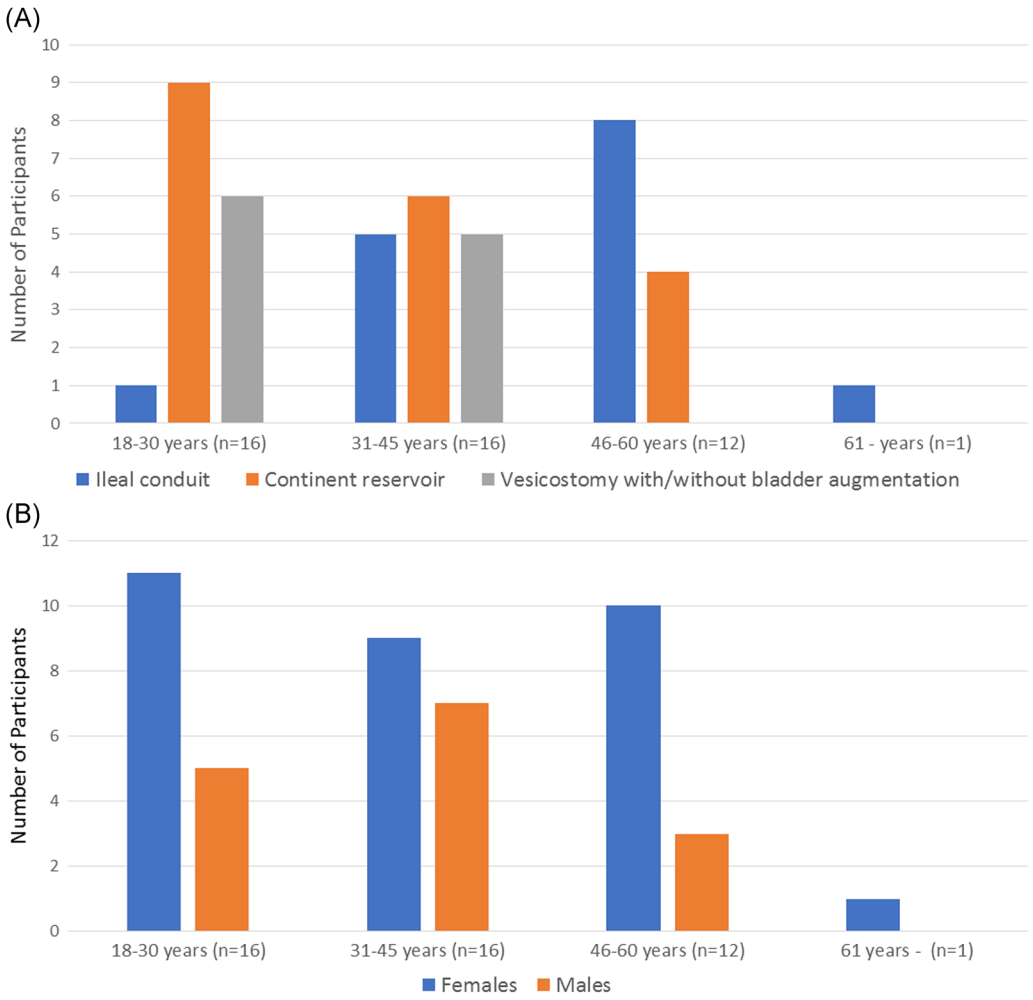

FIGURE 2 A, Type of major surgery in the different age groups. B, Type of major surgery in females and males

As many as 172 patients (88%) did not need any assistance emptying the bladder. The remaining 24 (12%) needed help in various ways, from a reminder to empty the bladder to total assistance. Eighteen (75%) of the patients needing assistance had been treated with a shunt due to concomitant hydrocephalus. Eight (33%) of the patients needing assistance to empty the bladder also had scoliosis and/or tethered cord syndrome.

Twenty-five (17%) of the 145 patients emptying the bladder via the urethra, spontaneously or with CIC, reported total continence but the majority (83%), reported they had urinary leakage. About 36% of the 145 patients experienced daily urinary leakage and urinary leakage was common in all the age groups (Figure 3A). In the group who reported total continence 73% were male. However, in the group of patients reporting daily leakage, males were also in majority (62%) (Figure 3B).

As many as 106 (54%) patients in the cohort did not report any urinary complications the year before the study. Eighty-four (43%) of the patients reported they had suffered from UTIs the year before they participated in this study and of these 47 (56%) reported three or more infections this year. Most of the infections were classified as low but 13 (15%) of them were infections in the upper urinary tract. Five patients were found to have a stone in the upper urinary tract and two patients had a stone in the urinary bladder substitute. Also, reflux was noted in one patient, three patients had dilated upper urinary tract, and one patient had suffered from an epididymitis.

Of all participants as many as 139 (71%) of the cohort did not report the use of any medication for urological problems. Anticholinergics was the most common drug, used by 42 patients (21%) in the total cohort. Long term antibiotics were used by eight patients (4%) and antiseptics were used by 11 patients (5%). Three patients (1.5%) reported to be treated with botulinum toxin A, against bladder overactivity.

Twenty-five patients (13%) had a reduced kidney function using the CKD grading system[10] with a lowered glomerular filtration (GFR) rate measured with cystatin C as compared with 20 patients (10%) when GFR for creatinine was used. Ten of the patients had a slightly lowered function (grade II) measured with cystatin C as compared with 15 patients using GFR for creatinine as

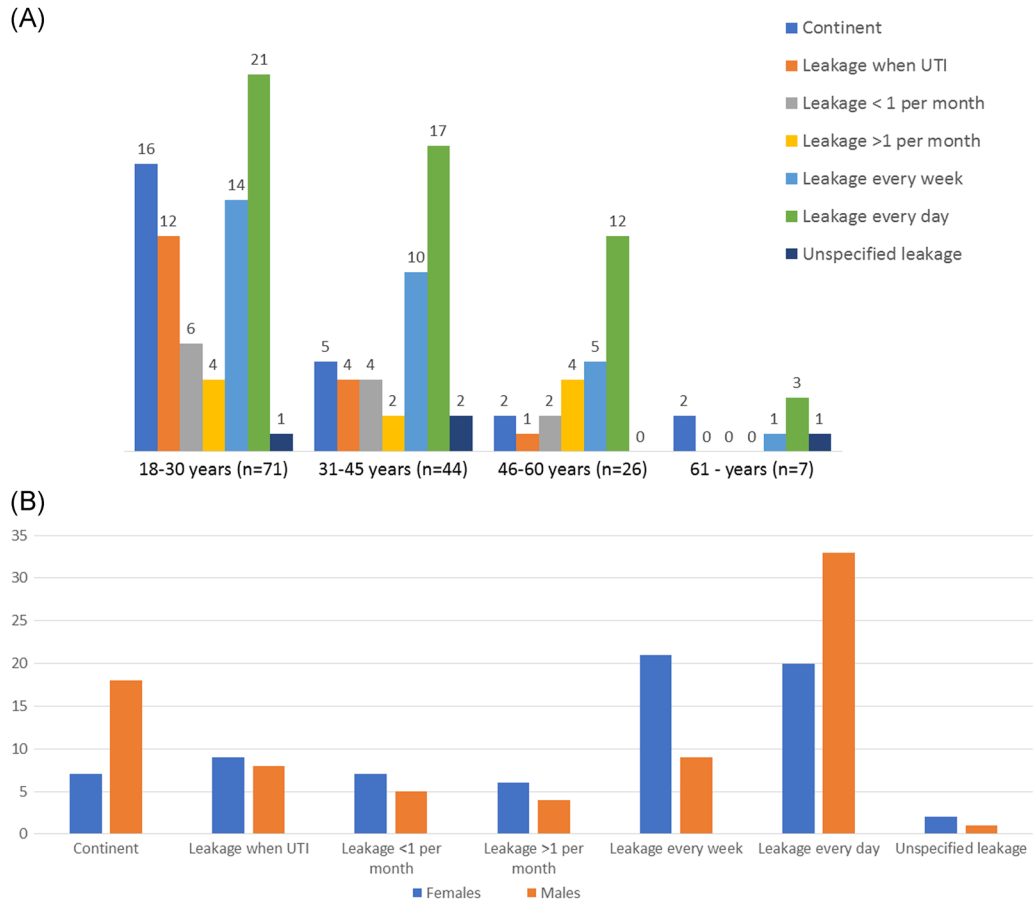

FIGURE 3 A, Urinary leakage in different age groups, persons voiding spontaneously or using CIC. B, Urinary leakage in females and male, persons voiding spontaneously or using CIC

method of assessment. Eleven patients had a moderately lowered function (grade III) measured with cystatin C but only one patient when using GFR for creatinine. In the four patients with severe renal dysfunction (grade IV and V), three of them were treated with dialysis or renal transplant, with no difference using GFR for cystatin C or creatine for the grading. The incidence of reduced kidney function was higher with successively older age, 8% (n = 7) in the group between 18 to 30 years, 10% (n = 10) in the group between 31 to 45 years, 21% (n = 8) in the group 46 to 60 years and 50% (n = 4) in the group between 61 to 73 years.

Most of the patients in the cohort, 123 (63%) reported that they emptied the bowel without problem. The remaining 73 (37%) patients used different techniques, such as strain, digital stimulation, compression of the abdomen, plucking (evacuating feces from the ampulla manually), transanal irrigation, antegrade irrigation, and colostomy (Figure 4). Leakage of feces was a problem for many patients and only 47 (24%) reported no problems, 75 (38%) suffered from leakage when they had diarrhea, 19 (10%) had fecal leakage less the once a month, 18 (9%) had fecal leakage more than once a month while 21 (11%) suffered from leakage every week and 14 (7%) experienced daily leakage with missing data for two patients.

The nonmyelomeningocele patients represented 8.7% (n = 17) of the total cohort. There was no need for assistance of others to empty the bladder or the bowel in any of the patients. Ten patients voided spontaneously and seven used CIC and of these, one patient had undergone bladder augmentation and one patient bladder augmentation in combination with a vesicostomy. Eight patients did not have any urinary leakage at all, two had a leakage when they had an UTI, four patients had leakage less than 1 per month, one patient had leakage every week, and three patients reported daily leakage. Thirteen patients did not have any complications and the remaining four reported UTI's. All patients in this subgroup had normal kidney function. Thirteen patients reported normal bowel emptying, two used strain, one person needed plucking, and one patient used transanal irrigation. The latter suffered from daily fecal leakage, whereas one patient reported fecal leakage less than 1 per month, three patients had problems with leakage when they hade diarrhea, and the other eight patients had no problem with fecal leakage. Two patients used long term antibiotics, one patient had oral treatment against overactive bladder and one patient was treated with α-1 blocker to enhance micturition.

4 | DISCUSSION

Most persons with SB reach adulthood today with a persistent need for urological care and functional bowel management. Since most patients with SB have a neurogenic bladder dysfunction with potential risk for renal impairment.[1] it is of great importance to follow the patients to prevent renal deterioration and to improve the quality of life by treating urinary leakage, reduce infections, and to avoid constipation and fecal leakage. This study includes 196 adult persons with SB representing a near-total regional population. Considering the large number of participants, this study contributes to knowledge about the function and dysfunction of the urinary bladder and the bowel in the total cohort during adult life, with the oldest patient being 73 years. Since the age range in our cohort is 18 to 73 years there is a variation in the care provided and the patients have been treated with the standard care of that time.

Both persons with myelomeningocele and persons with nonmyelomeningocele were included in the study. Persons in the latter group with spina bifida occulta and lipomyelomeningocele were as expected less affected but about 40% of them used CIC, two persons had major urological surgery, and also, urinary leakage and difficulties with emptying the bowel were not uncommon. Therefore, it seems important to continue to offer these persons care in a specialized unit.

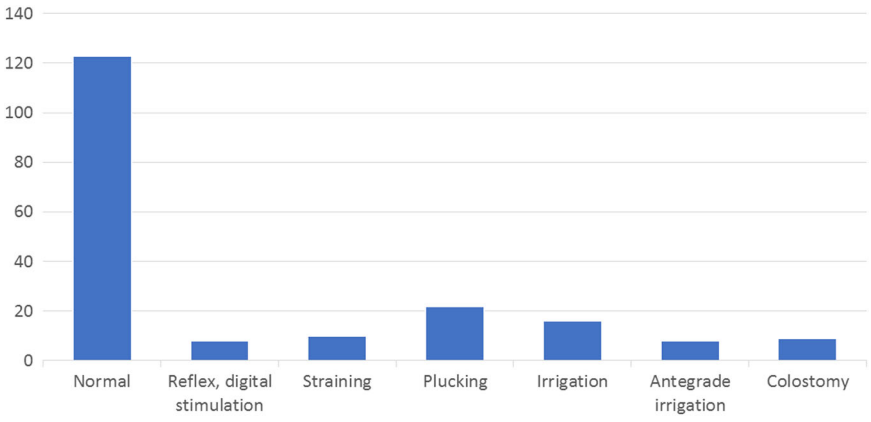

FIGURE 4 Methods for emptying the bowel

Today the standard method for emptying the bladder is CIC whenever possible. The majority used CIC when spontaneous voiding was not possible which is in line with reports from other centers.[2] The percentage of adult persons using CIC is expected to increase in the future since it is now the recommended way to empty the bladder and many persons in our studied population were born long before this method was introduced. As expected, only a few participants used straining to be able to void, which was the way most of these persons emptied the bladder before introduction of CIC and the use of indwelling catheters was very low.

An ileal conduit was the most common urinary diversion in patients over 45 years whereas a continent reservoir was the prevailing diversion in the ages below 45 years, but there is an increasing number of patients now operated with a vesicostomy with or without bladder augmentation. The type of surgery performed also has changed with time with an ileal conduit as standard when the eldest had their surgery, followed by continent reservoir and now bladder augmentation with or without vesicostomy as the preferred type of major surgery. This is also in line with what is reported in the literature.[2]

The percentage of persons reporting urinary leakage in our cohort was high, and only 17% were completely continent. In a pediatric cohort, about 40% reported continence[11] and in an adult population about 45% reported that they did not have problem with leakage.[2] It may be difficult to compare results between studies depending on how the question is presented and how the persons answer it, but the important point is that incontinence is very common in this patient group. In this study, we asked the persons how often they experienced leakage, but the quantity of the leakage is also important for the quality of life.[12] Taking into consideration the fact that only about 20% of the participants used anticholinergics, possible explanations may be that leakage is not a big problem, the medication does not help them, that it creates bad side-effects or that the patients forget to take the medication. Also, very few patients in our cohort were treated with botulinum toxin A at the time of the study, but this has already changed. Today, we follow a protocol first and foremost using anticholinergics followed by beta-3 stimulators or onabotulinum toxin A injections if oral medication is insufficient.

We compared GFR for cystatin C with GFR for creatinine to analyze the kidney function in this patient group. Cystatin C is considered to be a more sensitive method for analysis of kidney function in persons with reduced muscle mass.[13,14] GFR for cystatin C was found to detect more persons with a slightly decreased kidney function as compared with GFR for creatinine. Since early detection of reduced kidney function might serve as a warning signaling a need of more support to manage emptying the bladder, it is important to use as sensitive test as possible to try to prevent further renal damage.

Only a few of the participants used long term antibiotics as prophylaxis against urinary tract infections. This will hopefully further diminish since studies have shown that recurrence of infections occurs despite taking prophylaxis.[15] New strategies to prevent infections are under way, for example, instillation of gentamicin into the bladder regularly at night if the patient uses CIC.[16]

Constipation and fecal leakage can be very problematic for many patients with SB[1] and in this cohort more than a third of the patients had problems emptying the bowel and 19% experienced fecal leakage weekly or even daily. It has been shown that there is a correlation between bowel dysfunction and bladder dysfunction in persons with SB and when the bowel problems are managed, the urinary incontinence can be significantly reduced.[17] This is not yet common knowledge to all urologists and questions about bowel function should be included when evaluating the bladder function in these patients.

5 | CONCLUSION

In this study, we investigated the voiding conditions, renal function and bowel function in a cohort of almost all adult persons with SB in a regional area and found a large variation of grade of dysfunction from persons with almost no problems to persons with severely impaired function in all these aspects. A structured program for follow-up of adults with SB, customized depending on grade of urinary and bowel dysfunction might improve the health status in this group of persons. GFR for cystatin C, recommended as follow-up in this group of persons, was compared with GFR for creatinine and was found to be a more sensitive method to detect a slightly to moderately reduced kidney function. The Spina Bifida Association has created Guidelines for the care of people with spina bifida[18] that can be used when developing local follow-up programs.

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ETHICS STATEMENT

This study was approved by the Regional Ethical Review Board in Stockholm, Sweden (Dnr: 2014/1111-31).

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