Original Article

High prevalence of incontinence among young adults with spina bifida: description, prediction and problem perception

M Verhoef^{*,1}, M Lurvink¹, HA Barf¹, MWM Post^{1,4}, FWA van Asbeck^{1,2}, RHJM Gooskens³ and AJH Prevo^{1,2}

¹Rehabilitation Centre De Hoogstraat, Utrecht, The Netherlands; ²Department of Rehabilitation, Rudolf Magnus Institute of Neuroscience, University Medical Centre, Utrecht, The Netherlands; ³Department of Neurology and Neurosurgery, Rudolf Magnus Institute of Neuroscience, University Medical Centre, Utrecht, The Netherlands; ⁴IRV, Institute for Rehabilitation Research, Hoensbroek, The Netherlands

Study design: Cross-sectional study.

Objectives: To study the prevalence of incontinence, problem perception and determinants of urinary and faecal incontinence in young adults with spina bifida.

Setting: Nation-wide study in the Netherlands.

Participants: A total of 179 of 350 invited patients participated, including 37 patients with spina bifida occulta and 142 with spina bifida aperta, of whom 119 had hydrocephalus; 41% were male and mean age was 20.4 (range 16–25 years).

Methods: Data were collected from interviews, physical examination, neuropsychological tests and medical records.

Results: Urinary and faecal incontinence was common in young adults with spina bifida (60.9 and 34.1%, respectively), regardless of the bladder and bowel management they used. The majority of urinary and faecal incontinent patients perceived this as a problem (69.7 and 77.0%, respectively). Spina bifida aperta, hydrocephalus and a level of lesion of L5 or above were associated with patients suffering from urinary and/or faecal incontinence. Predictors of perceiving urinary incontinence as a problem were, in addition to being incontinent, not having hydrocephalus and having a level of lesion of L5 or above. The only predictor of perceiving faecal incontinence as a problem was the frequency of incontinence.

Conclusion: A majority of young adults with spina bifida suffer from urinary and faecal incontinence and most of them perceive their incontinence as a problem. Therefore, further efforts are important to improve urinary and faecal continence.

Spinal Cord (2005) 43, 331–340. doi:10.1038/sj.sc.3101705; Published online 1 February 2005

Keywords: spina bifida; incontinence; bladder management; bowel management; adolescents

Introduction

Spina bifida is a common anomaly with a worldwide incidence of 1:1000.¹ Before 1960, less than 10% of the patients survived infancy, whereas today their life expectancy is almost normal.^{1,2} This pronounced change in outcome, which has resulted from recent advances in medical technology, means that many patients with complex disabilities now survive into adulthood and entertain certain expectations of life. Therefore, it is important to examine the prevalence and predictors of the impairments they have to deal with. A common problem in patients with spina bifida is

incontinence,^{1,3–15} which is one of the secondary impairments that might affect their quality of life.¹⁶

Krogh *et al*¹⁰ found that 66% of the children with myelomeningocele aged 6 years or older who suffered from faecal incontinence reported that this problem had some or even a major influence on their social activities or quality of life. Lie *et al*¹¹ reported that three-quarters of the patients suffering from urinary incontinence regarded this as a stress factor. van Gool *et al*⁵ described that patients experienced even a slight improvement in urinary continence as a change for the better, as it meant that they gained some additional independence. Thus, reducing the frequency of incontinence as much as possible is an important goal of medical care.

An increasing number of studies have focused on the medical problems of spina bifida patients and several

*Correspondence: M Verhoef, Centre of Excellence for Rehabilitation Medicine Utrecht, Rehabilitation Centre De Hoogstraat, Rembrandtkade 10, 3583 TM Utrecht, The Netherlands

articles have reported on urinary and faecal incontinence.^{1,3–15} However, it is often difficult to compare the results of the various studies, because of differences in definitions and cutoff points, age of subjects, types of bladder and bowel management and types of spina bifida included. As a result, the reported prevalence of urinary and faecal incontinence in adolescent patients with spina bifida shows considerable variation across studies (46–80 and 13–71%, respectively).

Few studies have examined factors that influence incontinence.^{1,7,15} Furthermore, as far as we know, no studies have been published examining factors that relate to the perception of incontinence as a problem.

The purpose of the present study was to determine the prevalence of urinary and faecal incontinence and to determine the number of incontinent patients perceiving incontinence as a problem. We also studied relationships between patient characteristics (gender, hydrocephalus, type of spina bifida (*aperta* versus *occulta*), level of lesion, cognition and ambulation) on the one hand and incontinence and perceiving incontinence as a problem on the other. This study is part of the ASPINE study, a cross-sectional study on physical and cognitive disabilities, health care, participation in society and life satisfaction among Adolescents with SPina bifida In the NEtherlands.

Method

Participants

The study included patients with spina bifida (*aperta* and *occulta*, ICD-9-CM codes 741 and 756.17 respectively),¹⁷ aged between 16 and 25 years and living in the Netherlands. Patients who were unable to speak Dutch or who had comorbidity independently causing physical and/or mental problems were excluded.

Of the 12 spina bifida teams in the Netherlands, 11 co-operated with our study. The Dutch Association for Patients with Spina Bifida also invited members to participate and adverts were placed in two national magazines and on the Internet. In addition, rehabilitation centres, housing facilities and special schools were approached to find potential participants.

The medical ethics committee approved the ASPINE study. Informed consent was obtained from all participants.

Instruments

Data were collected from interviews, physical examination and neuropsychological testing, while data about medical history were collected from medical records. Data about urinary and faecal incontinence were collected by means of interviews. Urinary and faecal incontinence were defined as having one or more bladder or bowel accidents per month, requiring the need to change clothes or napkins, whether or not the patient used any kind of suprapubic, urethral or condom catheter. Patients were also asked if they perceived urinary incontinence, faecal incontinence,

constipation and abdominal pain as a problem. The interview also included questions about bowel or bladder management, assistance needed for daily toileting, time required for defecation and use of napkins. Patients sometimes used combinations of bladder and bowel management methods. Voiding spontaneously was defined as voluntary sensible voiding. Clean intermittent catheterisation (CIC) is catheterisation performed by others; clean intermittent self-catheterisation (CISC) is carried out by patients themselves. The Crde manoeuvre is a method of emptying the bladder by applying external pressure to the lower abdomen. Furthermore, patients used different catheters (suprapubic or urethral indwelling), while some had had surgery (urinary diversion or sphincterotomy). As regards bowel control, patients were asked if they were on a special diet as part of their bowel management or if they used oral laxatives. Patients were also asked whether they used anal stimulating laxatives like enemas (phosphate or Microlax[®] microenemas) or suppositories. Other methods inquired about were retrograde colonic washout and manual evacuation.

The subsequent physical examination determined the sensory level of lesion on the basis of the International Standards for Neurological and Functional Classification of Spinal Cord Injury.^{18,19} Based on anatomy, we identified two subgroups: those with a lesion level of L5 or above and those with a lesion level of S1 or below. This subdivision was made because the most important centre for bladder control and bowel control is below S1. Motor innervations to the muscles of the fundus of the bladder, which control bladder contraction, arise from the parasympathetic nerves at the S2–S4 level. Motor nerves to the external sphincter arise from the pudendal nerve coming from S2–S4.²⁰

Cognitive functioning was determined with an intelligence test, the Raven Standard Progressive Matrices.^{21,22} The mean intelligence quotient (IQ) of the general population is 100, with a standard deviation of 15. Persons with an IQ score of 70 or below are classified as mentally retarded.

Ambulation was assessed using the Hoffer criteria.²³ For the purpose of the present article, we distinguished two groups with respect to ambulation. The first group consisted of community ambulators and household ambulators and was called ambulatory. The second group consisted of exercise ambulators and patients who are wheelchair-bound and was called wheelchair-dependent.

Statistical analysis

Data were analysed with descriptive statistics using SPSS version 10. Relationships between bladder and bowel management and other variables are displayed in contingency tables. χ^2 tests were used to determine if possible predictors and outcomes were related. A *P*-value below 0.05 indicates a significant relationship between the predictor variable and the dependent variable.

A backward stepwise logistic regression analysis was conducted to determine the predictive value of the different variables for urinary incontinence, faecal incontinence, perceiving urinary incontinence as a problem and perceiving faecal incontinence as a problem. The independent variables in this model were gender, type of spina bifida, hydrocephalus, level of lesion, cognitive functioning and ambulatory status. Frequency of incontinence was added in the logistic regression analysis for the dependent variables of perceiving urinary or faecal incontinence as problems. All variables were dichotomised.

Results

Study population

A total of 350 patients were invited by mail to participate in the study, of whom 181 expressed their willingness to participate. Reasons for not participating were known for 20% of the nonparticipants; these included unknown address for one third, lack of time for another third and other reasons for the remaining patients. No significant differences between participants and nonparticipants were found as regards age, gender, type of spina bifida, level of defect and having been shunted for hydrocephalus. Two of the patients who had agreed to participate were excluded because of comorbidity independently inducing serious physical and/or mental disorders: one patient had a serious heart disease and one had a chromosome disorder. This left 179 Dutch participants to be included in the study.

Of the 179 participants, 142 patients were patients with spina bifida aperta and 37 were patients with spina bifida occulta. Of the 142 patients with spina bifida aperta, 109 were diagnosed as having myelomeningocele, 13 as having meningocele and 20 as unspecified aperta. The 37 patients with spina bifida occulta included all 15 patients who were diagnosed as having a lipoma. Of the total group of patients, 119 (66.5%) suffered from hydrocephalus, all of them with spina bifida aperta. There were 105 women and 74 men, aged from 16 to 25 years (mean age 20.4 years, SD = 3.0). Of the total group, 141 patients (78.8%) had a level of

lesion of L5 or above and 38 patients (21.2%) had a level of lesion of S1 or below. IQ scores of 11 patients (6.1%) were missing; 20 patients (11.2%) were mentally retarded ($IQ \leq 70$). Finally, 109 patients (60.9%) were ambulatory and 70 patients (39.1%) were wheelchair-dependent.

Prevalence of incontinence and perceiving incontinence as a problem

According to the definition used in the present study (having accidents once a month or more), 109 of the 179 patients (60.9%) suffered from urinary incontinence. Of these 109 incontinent patients, 76 (69.7%) perceived their incontinence as a problem (Table 1). The prevalence of faecal incontinence was 34.1% (61 of the 179 patients). Of these 61 persons, 47 (77.0%) perceived their faecal incontinence as a problem (Table 1). A total of 47 patients (26.3%) were both urinary and faecal incontinent, and 56 patients (31.3%) were not incontinent at all.

Table 1 allows a relationship to be inferred between the frequency of incontinence and the perception of incontinence as a problem. Incontinence that occurred less than once a month was perceived as a problem by a minority only. In contrast, incontinence occurring more than once a month was perceived as a problem by most patients.

Bladder management

Table 2 describes the bladder management methods and the percentages of patients using a particular method who were incontinent and perceived incontinence as a problem. One-third of our patient group voided spontaneously (31.3%) and a quarter of all patients (24.6%) did not use any specific bladder management method at all. All other patients used one or more bladder management techniques, of which CISC was the most common (60.3% of all persons). Many combinations of methods were used, CISC and urinary diversion being the most common combination (23 persons).

Of all patients who voided spontaneously, more than a third (39.3%) suffered from urinary incontinence and nearly all of them (86.4%) perceived their incontinence

Table 1 Frequency of incontinence for urine and faeces related to the perception of incontinence as a problem by young adults with spina bifida

	Frequency of incontinence					Total
	Never	$< 1 \times /month$	$1-4 \times /month$	$1-7 \times /week$	$\geq 1 \times /day$	
<i>Urinary incontinence</i>						
Perceived as a problem (%)	0 (0.0)	9 (37.5)	31 (73.8)	13 (65.0)	32 (68.1)	85 (47.5)
Perceived as no problem (%)	46 (100)	15 (62.5)	11 (26.2)	7 (35.0)	15 (31.9)	94 (52.5)
<i>Faecal incontinence</i>						
Perceived as a problem (%)	1 (1.3)	20 (46.5)	30 (73.2)	15 (88.2)	2 (66.7)	68 (38.0)
Perceived as no problem (%)	74 (98.7)	23 (53.5)	11 (26.8)	2 (11.8)	1 (33.3)	111 (62.0)

Note: Figures within parentheses are column percentages

Table 2 Methods of bladder management used by young adults with spina bifida, with numbers of patients using a particular method and being urinary incontinent and numbers of incontinent patients using a particular method and perceiving urinary incontinence as a problem

<i>Bladder management</i>	<i>Number of patients using method (%)</i>	<i>Combined with other methods</i>	<i>Incontinent patients using method (% of all)^a</i>	<i>Incontinence a problem (% of incontinent patients)^b</i>
Voiding spontaneously	56 (31.3)	12	22 (39.3)	19 (86.4)
CIC ^c	10 (5.6)	4	6 (60.0)	4 (66.7)
CISC ^d	108 (60.3)	29	78 (72.2)	52 (66.7)
Crédé	9 (5.0)	7	8 (88.9)	8 (100.0)
Suprapubic catheter	2 (1.1)	0	1 (50.0)	1 (100.0)
Indwelling catheter	1 (0.6)	0	0 (0.0)	—
Urinary diversion	24 (13.4)	24	12 (50.0)	8 (66.7)
Urinary sphincter	2 (1.1)	2	1 (50.0)	0 (0.0)
Other	8 (4.5)	4	8 (100.0)	5 (62.5)

^aPercentage of all patients using this particular method of bladder management^bPercentage of incontinent patients using this particular method of bladder management^cClean intermittent catheterization^dClean intermittent self-catheterization**Table 3** Methods of bowel management used by young adults with spina bifida, with numbers of patients using a particular method and being incontinent, numbers of incontinent patients using a particular method and perceiving faecal incontinence as a problem and numbers of patients perceiving constipation and abdominal pain as a problem

<i>Bowel management</i>	<i>Number of patients using method (%)</i>	<i>Combined with other methods</i>	<i>Incontinent patients using method (% of all)^a</i>	<i>Incontinence a problem (% of incontinent patients)^b</i>	<i>Constipation a problem (% of all)^a</i>	<i>Abdominal pain a problem (% of all)^a</i>
No management	82 (45.8)	0	18 (22.0)	15 (83.3)	27 (32.9)	27 (32.9)
Diet	4 (2.2)	4	2 (50.0)	2 (100.0)	2 (50.0)	2 (50.0)
Laxatives	31 (17.3)	21	12 (38.7)	6 (50.0)	18 (58.1)	12 (38.7)
Retrograde colonic washout	49 (27.4)	17	23 (46.9)	20 (87.0)	18 (36.7)	17 (34.7)
Phosphate enemas	2 (1.1)	2	2 (100.0)	1 (50.0)	2 (100.0)	1 (50.0)
Microlax [®]	8 (4.5)	5	5 (62.5)	4 (80.0)	6 (75.0)	4 (50.0)
Suppositories	2 (1.1)	2	0 (0.0)	—	2 (100.0)	1 (50.0)
Manual evacuation	27 (15.1)	11	11 (40.7)	9 (81.8)	15 (55.6)	9 (33.3)
Other	10 (5.6)	7	4 (40.0)	2 (50.0)	7 (70.0)	5 (50.0)

^aPercentage of all patients using this particular method of bowel management^bPercentage of incontinent patients using this particular method of bladder management

as a problem. The majority of patients using some form of bladder management were nevertheless incontinent. Urinary incontinence was particularly common in the few patients using the Crd manoeuvre (88.9%) and patients using CISC (72.2%). Of the 85 patients using CISC without urinary diversion, 67 (78.8%) were incontinent. Patients who used a specific bladder management technique but were still incontinent were less likely to perceive their incontinence as a problem (50.0–66.7%) than patients who voided spontaneously and were incontinent (86.4%), with the exception of those using the Crd manoeuvre and a suprapubic catheter.

Medications used for bladder management related to continence included oral bladder spasmolytics (24.0%) and intravesical oxybutynin (4.5%).

Bowel management

Table 3 describes bowel management methods and the percentages of patients who were faecal incontinent and perceived faecal incontinence as a problem. It also shows the numbers of patients who perceived constipation or abdominal pain as a problem. Nearly half of our patients did not use any specific bowel management technique (45.8%) at all. One-fifth of this group were incontinent (22.0%) and nearly all of them perceived their faecal incontinence as a problem (83.3%). The most common method used for bowel management was retrograde colonic washout (27.4%). Oral laxatives and manual evacuation were also common methods (17.3 and 15.1%, respectively). The most common combination of methods was retrograde colonic washout and oral laxatives (11 persons).

Few patients reported dieting as part of bowel management. The prevalence of faecal incontinence in patients using the various bowel management methods varied from 38.7 to 62.5%, with the exception of two patients who used phosphate enemas (both incontinent) and two patients who used suppositories (both continent). The percentages of patients perceiving incontinence as a problem were particularly high among incontinent patients using retrograde colonic washout (87.0%), Microlax[®] (80.0%) or manual evacuation (81.8%). Regardless of the method of bowel management, more than half of the patients perceived constipation as a problem, except for those who used retrograde colonic washout (36.7%) and those who used no method at all (32.9%). Regardless of the management method, less than half of the patients perceived abdominal pain as a problem (32.9–50.0%).

Other aspects of bladder and bowel control

Antibiotics Antibiotics were used continuously by 29.6% of the patients to prevent urinary tract infection. Of the 179 patients, 111 (62.0%) had had to use high doses of antibiotic agents more than once in the year preceding the study to manage a urinary tract infection.

Use of diapers Of the 179 patients, 114 (63.7%) used diapers. Patients with urinary incontinence used diapers far more often (98; 90.7%) than continent persons (16; 23.5%). Of the 60 patients with faecal incontinence, 53 (88.3%) used diapers.

Assistance with daily toileting A total of 32 patients (17.9%) needed assistance with daily toileting. Of these patients, 23 (71.9%) were urinary incontinent and 19 patients (59.4%) were faecal incontinent.

Time needed for defecation In our study, 58 patients (32.4%) needed 15 min or more a day for defecation. Of the patients who needed 15 min or more, 30 (51.7%) were faecal incontinent. In all, 38 of the 49 patients (77.6%) who evacuated their bowel by retrograde colonic washout, one of the two patients who used phosphate enemas, six of the eight patients who used Microlax[®] and five of the 22 patients who used manual evacuation needed 15 min or more a day for defecation. None of the patients who used suppositories needed 15 min or more.

Predictors of incontinence and perceiving incontinence as a problem

Gender Urinary incontinence was present in 64.9% of the men and 58.1% of the women, and faecal incontinence was present in 32.4% of the men and 35.2% of the women, with no significant relationships either between gender and urinary or faecal incontinence or

between gender and the perception of urinary or faecal incontinence as a problem (Table 4).

Type of spina bifida Patients with spina bifida aperta had a higher prevalence of urinary incontinence than those with spina bifida occulta (67.6 and 35.1%, respectively; $P=0.001$). However, of these incontinent patients, those with spina bifida occulta were more likely than those with spina bifida aperta to perceive their incontinence as a problem (100.0 and 65.6%, respectively; $P=0.009$). Patients with spina bifida aperta had a higher prevalence of faecal incontinence than those with spina bifida occulta (40.8 and 8.1%, respectively; $P=0.000$). The relationship between the type of spina bifida and the perception of faecal incontinence as a problem was not significant.

Hydrocephalus Patients with hydrocephalus were more likely to suffer from urinary incontinence than those without hydrocephalus (70.6 and 41.7%, respectively; $P=0.000$). Patients with hydrocephalus had a higher prevalence of faecal incontinence than those without hydrocephalus (46.2 and 10.0%, respectively; $P=0.000$). More patients without hydrocephalus reported perceiving incontinence as a problem, although this relationship between hydrocephalus and the perception of incontinence for urine or faeces as a problem was not significant.

Level of lesion Patients with a level of lesion of L5 or above were more likely to be incontinent for urine than patients with a lesion S1 or below (68.8 and 31.6%, respectively; $P=0.000$). Patients with a level of lesion of L5 or above were more likely to suffer from faecal incontinence than patients with a lesion level of S1 or below (39.7 and 13.2%, respectively; $P=0.002$). There was no significant relationship between the level of lesion and the perception of urinary or faecal incontinence as a problem.

Cognition There was no significant relationship between IQ and urinary and faecal incontinence, nor between IQ and the perception of urinary and faecal incontinence as a problem.

Mobility A larger percentage of wheelchair-dependent patients than ambulatory patients suffered from urinary incontinence (72.9 and 53.2%, respectively; $P=0.012$). Wheelchair-dependent patients were more likely than ambulatory patients to suffer from faecal incontinence (48.6 and 24.8%, respectively; $P=0.001$). The relationship between mobility and the perception of urinary and faecal incontinence as a problem was not significant, although ambulatory patients seemed to be more likely to perceive faecal incontinence as a problem than did wheelchair-dependent patients.

Table 4 Relationships between gender, spina bifida characteristics and resulting disabilities, and prevalence of incontinence and perceiving incontinence as a problem in young adults with spina bifida

	Gender		Type of spina bifida			Hydrocephalus		Level of lesion			Cognition		Ambulation	
	Male	Female	Aperta	Occulta		Yes	No	...-L5	SI-...		IQ ≤ 70	IQ > 70	Non	Ambulant
Urine														
Incontinent (%)	48 (64.9)	61 (58.1)	96 (67.6)	13 (35.1) ^a		84 (70.6)	25 (41.7) ^a	97 (68.8)	12 (31.6) ^a		15 (65.2)	87 (60.0)	51 (72.9)	58 (53.2) ^a
→ Perceived as problem (%)	29 (60.4)	47 (77.0)	63 (65.6)	13 (100) ^a		55 (65.5)	21 (84.0)	69 (71.1)	7 (58.3)		10 (66.7)	61 (70.1)	34 (66.7)	42 (72.4)
Faeces														
Incontinent (%)	24 (32.4)	37 (35.2)	58 (40.8)	3 (8.1) ^a		55 (46.2)	6 (10) ^a	56 (39.7)	5 (13.2) ^a		12 (52.2)	46 (31.7)	34 (48.6)	27 (24.8) ^a
→ Perceived as problem (%)	18 (75.0)	29 (78.4)	45 (77.6)	2 (66.7)		42 (76.4)	5 (83.3)	42 (75.0)	5 (100)		9 (75.0)	36 (78.3)	23 (67.6)	24 (88.9)

^aSignificant difference between subgroups, Pearson's χ^2 P-value < 0.05

Logistic regression analysis

The joint predictive values of all the above variables for the frequency of urinary and faecal incontinence and problem perception were tested using a backward stepwise logistic regression analysis (Table 5). Type of spina bifida and level of lesion were found to be significant predictors of urinary incontinence. Patients with spina bifida aperta were about 2.7 times more likely to suffer from urinary incontinence than those with spina bifida occulta. Patients with a level of lesion of L5 or above were 3.2 times more likely to be incontinent for urine than those with lower lesions.

We also tested the predictive values of all the above-mentioned variables for the perception of urinary incontinence as a problem. The frequency of incontinence was also added in this model. Continence, hydrocephalus and level of lesion were found to be significant predictors. Patients who were incontinent for urine (accidents at least once a month) were 18.9 times more likely to perceive incontinence as a problem. Patients without hydrocephalus were 3.3 times more likely to perceive incontinence as a problem than those with hydrocephalus. Patients with a level of lesion of L5 and above were 3.5 times more likely to perceive their urinary incontinence as a problem than those with a level of lesion of S1 and below.

One predictor was found for faecal incontinence: patients with hydrocephalus were 9.5 times more likely to be incontinent for faeces. The only predictor we found for perceiving faecal incontinence as a problem was the frequency of incontinence, with incontinent patients (accidents at least once a month) being 12.2 times more likely to perceive this as a problem than continent patients. There was a trend for aperta patients to more often perceive faecal incontinence as a problem than occulta patients, but this difference was not significant.

Discussion

This cross-sectional study evaluated urinary and faecal incontinence in young adults with spina bifida (myelomeningocele, meningocele and occult spina bifida). We found that incontinence was common in young adults with spina bifida, despite the use of various bladder and bowel management techniques. The majority of incontinent patients perceived their incontinence as a problem. Spina bifida aperta, hydrocephalus and a level of lesion of L5 or above were associated with patients suffering from urinary and/or faecal incontinence. Predictors of perceiving urinary incontinence as a problem were, in addition to being incontinent, not having hydrocephalus and having a level of lesion of L5 or above. The only predictor of perceiving faecal incontinence as a problem was frequency of incontinence.

Prevalence of incontinence

The present study showed that most young adults with spina bifida suffered from urinary incontinence and

Table 5 Predictors of frequency of incontinence and perceiving urinary and faecal incontinence as a problem in young adults with spina bifida

	<i>Frequency of urinary incontinence</i>		<i>Perceiving urinary incontinence as problem</i>		<i>Frequency of faecal incontinence</i>		<i>Perceiving faecal incontinence as problem</i>	
	P-value	Odds ratio	P-value	Odds ratio	P-value	Odds ratio	P-value	Odds ratio
Continence 0 = continent 1 = incontinent	X	X	0.000	18.903	X	X	0.000	12.187
Gender 0 = female 1 = male	—	—	—	—	—	—	—	—
Hydrocephalus 0 = no hydrocephalus 1 = hydrocephalus	—	—	0.034	0.327	0.000	9.503	—	—
Type of spina bifida 0 = occulta 1 = aperta	0.016	2.749	—	—	—	—	0.066	2.826
Level of lesion 0 = S1 and below 1 = L5 and above	0.008	3.179	0.036	3.533	—	—	—	—
Intelligence quotient 0 = > 70 1 = ≤ 70	—	—	—	—	—	—	—	—
Ambulation 0 = ambulatory 1 = wheelchair- dependent	—	—	—	—	—	—	—	—

approximately one-third of the patients suffered from faecal incontinence. In all, a quarter of the patients were both urinary and faecal incontinent. Because of differences in definitions used, it is difficult to compare our values with those found in other studies, especially with regard to urinary incontinence. We defined both urinary and faecal incontinence as having one or more accidents per month. As far as faecal incontinence is concerned, this definition corresponds to that used in most other studies, and the percentages found are indeed comparable.^{7,10,13,15} By contrast, the definition of urinary incontinence varies across studies. In our study, we used a cutoff point of once a month, whereas most studies used other definitions, like socially dry, meaning dry intervals for at least 2 or 3 h.^{6,9,11} Hagelsteen *et al*⁶ found that one-quarter of their patients were socially dry and 14% were completely dry. Lie *et al*¹¹ found that one-fifth of the adolescents aged 13–18 years were socially dry (3 h). In our study, 25% of the 179 patients never had accidents for urine incontinence, a percentage that is similar to that found by Hunt and Poulton²⁴ for young adults being reliably dry and clean without any padding or appliance. We found a clear relationship between having less than one

accident per month or having one or more accidents per month and the perception of urinary incontinence as a problem. This relationship might justify the choice of this cutoff point for incontinence in future research.

Perception of incontinence as a problem

More than two-thirds of the patients with urinary incontinence in our study and more than three-quarters of those with faecal incontinence perceived their incontinence as a problem. Few studies have reported patients' perceptions of incontinence. Krogh *et al*¹⁰ found that 66% of the patients suffering from faecal incontinence reported that faecal incontinence had some or even a major influence on their social activities or quality of life. Lie *et al*¹¹ showed that 77% of the patients with urinary incontinence and 75% of the patients with faecal incontinence regarded this as a moderate or severe stress factor. These results are in reasonable agreement with ours.

Bladder management

One-third of the 179 patients in the present study voided spontaneously, and one-quarter used this as the only

method, which is comparable to what was found in other studies.^{11,12} More than one-third of all patients who voided spontaneously, however, suffered from urinary incontinence, which is comparable to the 29% of patients being wet reported by Malone *et al*,¹² while Lie *et al*¹¹ found that 31% were constantly wet and 28% had control for less than 3 h.

As in other studies, most patients in our study emptied their bladder through CISC.^{2,6,11,14} Three-quarters of patients using this method suffered from urinary incontinence. This high percentage is comparable to those reported in the literature. Malone *et al*¹² described that 70% of patients using intermittent catheterization were wet, and Lie *et al*¹¹ found that 27% were constantly wet and 45% had control for less than 3 h. By contrast, Bowman *et al*² found that 83% of patients on CIC were dry most of the time. These differences in literature findings may be due to differences in definition.

Although CISC is partly used to protect against renal deterioration,²⁵ we had expected greater benefit from this method in terms of continence. Perhaps this method is not carried out optimally by many patients, which might be related to possible cognitive impairments. However, intelligence quotient was not a predictor of incontinence in the present study. Further study on self-care competencies in this patient group is recommended.

The Crd manoeuvre was used by 5% of patients, even though this method is now regarded as obsolete because of the risk of kidney damage.

Half of the patients who had undergone surgery were continent, while the other half were still suffering from incontinence. We cannot conclude, however, that surgery is not useful, because without surgery even higher percentages for incontinence might have been found; a cross-sectional study like this is unable to evaluate the effect of surgery on incontinence. The literature provides varying percentages of continence for different forms of surgical treatment of children with neurogenic sphincteric incompetence, ranging from 5 to 100%.²⁶ Further study of predictors of the outcome of incontinence surgery might help us select patients who benefit from surgery.

Bowel management

Of all patients in our study, a quarter emptied their bowel through retrograde colonic washout. The literature provides two studies describing colonic washout: whereas the results found by Knab *et al*⁸ agree with our findings, Wright¹⁵ found a higher proportion. In our study, 15% of the patients used manual evacuation. This is comparable to what Knab *et al*⁸ found, although other studies found higher percentages, ranging from 25 to 41%.^{6,11,12,15} Findings of previous studies show more frequent use of suppositories and enemas than ours.^{8,10,12}

Other aspects of bladder and bowel management

Use of napkins Two-thirds of our population used napkins, which is in agreement with the findings of other studies.^{6,10–12} No relationship was found between the use of napkins and the perception of incontinence as a problem. Apparently, the possible social embarrassment of having accidents of urine or faecal soiling does not outweigh the discomfort of wearing a napkin.

Assistance with daily toileting Several studies have reported that independence is an important aspect of personal care.^{5,6,8} A minority of our study population (17.9%) needed assistance with daily toileting. Other studies reported much higher figures for the need of assistance, which seems to depend on methods of bladder and bowel management.^{6,8,10,11} The highest percentages have been reported for bowel management, especially manual evacuation and retrograde colonic washout.^{8,11} Krogh *et al*¹⁰ found that 59% needed help with defecation. In our study, patients who needed assistance were not more likely to perceive incontinence as a problem.

Time needed for defecation One-third of the patients needed 15 min or more a day for defecation; these were mostly patients using retrograde colonic washout. Krogh *et al*¹⁰ reported that half of the patients in their study needed 15 min or more, and Knab *et al*⁸ found that most of the methods did not take more than 15 min, except for retrograde irrigation and suppositories. The time patients needed for defecation was apparently not an important factor in perceiving incontinence as a problem in our study.

Predictors of incontinence and perceiving incontinence as a problem

Gender Just as many men as women in our study were incontinent, which was true for both urine and faeces. Other studies have reported that more males than females were urinary incontinent,^{6,11} possible explanations being anatomical differences affecting manual compression, differences in care for hygiene and boys being more likely to give up catheterisation. Based on our definition of incontinence, we expected more men to be continent, because they are able to use condom catheters. This may have cancelled out the gender effect found in other studies.

Type of spina bifida Only two studies mentioned patients with spina bifida occulta in their study population, and neither of them described results specifically for this group.^{8,27} Most research has been carried out on spina bifida aperta patients. Most patients in our study who were both urinary and faecal incontinent were patients with spina bifida aperta, but it is important to note that incontinent patients with spina

bifida occulta were more likely to perceive their urinary incontinence as a problem than those with spina bifida aperta. However, our logistic regression analysis of all predictors together showed that type of spina bifida was not a significant predictor. This may be due to the relationships between this variable and other predictive variables.

Hydrocephalus In our study, patients with hydrocephalus were more likely to be incontinent for urine as well as faeces. However, urine-incontinent patients without hydrocephalus were more likely to perceive this as a problem than those with hydrocephalus. This was confirmed by the logistic regression analysis, which showed that not having hydrocephalus was a predictor of being more likely to perceive urine incontinence as a problem. The explanation for this finding might relate to the different social situations: patients with hydrocephalus are more likely to attend special schools or to work in sheltered workplaces than patients without hydrocephalus, which means that episodes of incontinence might be less embarrassing to them than to patients without hydrocephalus. Wright¹⁵ described that bowel continence was mentioned by each of their participants as an important factor in being able to meet work and social commitments. By contrast, Bomalaski *et al*¹ reported that incontinence in this patient group was not an obstacle to employment.

Level of lesion Based on anatomical differences, we decided to split the group into patients with a level of spinal lesion of L5 or above and those with a level of lesion of S1 or below.^{14,20} Mevorach *et al*¹⁴ found that clinical neurological function was a poor indicator of lower urinary tract dysfunction and that ambulatory children with spina bifida suffered the full spectrum of lower urinary tract infections. However, in our study, patients with a level of lesion of L5 or above were far more likely to be urinary and faecal incontinent than those with a level of lesion of S1 or below. Patients with a level of lesion of L5 and above were also more likely to perceive urinary incontinence as a problem when corrected for frequency of incontinence and hydrocephalus in the logistic regression analysis.

Cognition Our study found no significant relationships between cognition and incontinence. As far as we know, no studies are available to compare these results with. An influence of IQ was expected, however, and the reason for not finding such a relationship remains unclear.

Mobility Our study found a relationship between mobility and incontinence. Wheelchair-dependent patients were more likely to be urinary and faecal incontinent than ambulatory patients. Mevorach *et al*¹⁴ reported that patients who were able to walk had the

same risk of lower urinary tract difficulties than their nonambulatory peers. Knoll and Madersbacher⁹ found that wheelchair-bound patients were more prone to stay socially dry than walkers among patients with areflexia of the detrusor combined with areflexia of the pelvic floor, the largest group of their study. Wright¹⁵ hypothesised that patients' mobility or lack of it would affect the maintenance of good bowel habits, but their results did not demonstrate this. Mobility probably does not affect incontinence by itself, and an explanation for our finding could be that patients with more severe spina bifida are more likely to be both wheelchair users and incontinent. This explanation is supported by the logistic regression analysis, in which mobility was no longer a significant predictor.

Limitations

Our study was subject to a few limitations. The response rate was lower than expected (50%), but no significant differences were found between the study population and the nonparticipants in terms of type and level of spina bifida and demographic variables. It is therefore unlikely that the nonresponse has seriously biased the results of this study. However, there still might be some selection bias, especially for spina bifida occulta patients, because only patients suffering from problems or having obvious skin signs are known to the spina bifida teams. Furthermore, the population of Dutch young adults with spina bifida might differ from patient groups in other countries because of differences in medical care and cultural aspects.

Recommendations

Most patients perceived incontinence as a problem and it is therefore important to reduce the frequency of incontinence as much as possible, preferably to less than once a month (if complete continence is not possible). The best management technique (in terms of incontinence) needs to be assessed for each individual patient. Patients should be trained and if necessary retrained, and management should be regularly evaluated. One should not hesitate to try other methods of bladder or bowel management for patients suffering from problems, although radical surgical management techniques should be considered carefully before use.

Acknowledgements

This study was supported by the Johanna Children's Fund (Arnhem, The Netherlands) and Stinafo (The Hague, The Netherlands). We thank Olga de Wit and Maaïke Dekker for their contribution in collecting the data. We also thank the BOSK patients association, the organisations for sheltered homes and the following centres for their participation in this study: Academic Medical Centre Amsterdam, Franciscusoord mytyschool Houthem, Isala Clinics Zwolle, University Medical Centre Leiden, Rehabilitation Centre Het Roessingh Enschede, Rehabilitation Centre Revalidatie Friesland, Rehabilitation Centre Tolbrug, St Elisabeth Hospital Tilburg,

University Medical Centre Nijmegen, University Medical Centre Utrecht, University Hospital Rotterdam, University Hospital Maastricht, Medical Centre of the Free University Amsterdam and Werkenrode Groesbeek. Finally, we are most grateful to all patients who participated in this study.

References

- Bomalaski MD, Teague JL, Brooks B. The long-term impact of urological management on the quality of life of children with spina bifida. *J Urol* 1995; **154**: 778–781.
- Bowman RM, McLone DG, Grant JA, Tomita T, Ito JA. Spina bifida outcome: a 25-year prospective. *Pediatr Neurosurg* 2001; **34**: 114–120.
- Bax MC, Smyth DP, Thomas AP. Health care of physically handicapped young adults. *Br Med J Clin Res Ed* 1988; **296**: 1153–1155.
- Dietrich S, Okamoto G. Bowel training for children with neurogenic dysfunction, a follow-up. *Arch Phys Med Rehabil* 1982; **63**: 166–170.
- van-Gool JD, Jong TPVMD. Urinary infection, incontinence and clean intermittent catheterisation in myelomeningocele. *Z Kinderchir* 1990; **45**: 10.
- Hagelsteen JH et al. Disability in children with myelomeningocele. *Acta Paediatr Scand* 1989; **78**: 721–727.
- King JC, Currie DM, Wright E. Bowel training in spina bifida: importance of education, patient compliance, age, and anal reflexes. *Arch Phys Med Rehabil* 1994; **75**: 243–247.
- Knab K, Langhans B, Behrens R, Strehl AE. The neuropathic bowel in spina bifida – a cross-sectional study in 226 patients. *Eur J Pediatr Surg* 2001; **11**(Suppl 1): S41–S42.
- Knoll M, Madersbacher H. The chances of a spina bifida patient becoming continent/socially dry by conservative therapy. *Paraplegia* 1993; **31**: 22–27.
- Krogh K, Lie HR, Bilenberg N, Laurberg S. Bowel function in Danish children with myelomeningocele. *APMIS Suppl* 2003; **109**: 81–85.
- Lie HR et al. Bowel and bladder control of children with myelomeningocele: a Nordic study. *Dev Med Child Neurol* 1991; **33**: 1053–1061.
- Malone PS, Wheeler RA, Williams JE. Continence in patients with spina bifida: long term results. *Arch Dis Child* 1994; **70**: 107–110.
- McAndrew I. Adolescents and young people with spina bifida. *Dev Med Child Neurol* 1979; **21**: 619–629.
- Mevorach RA, Bogaert GA, Baskin LS, Lazzaretti CC, Edwards MS, Kogan BA. Lower urinary tract function in ambulatory children with spina bifida. *Br J Urol* 1996; **77**: 593–596.
- Wright L. The efficacy of bowel management in the adult with spina bifida. *Eur J Pediatr Surg* 2002; **12**(Suppl 1): S41–S43.
- Broome BA. The impact of urinary incontinence on self-efficacy and quality of life. *Health Qual Life Outcomes* 2003; **1**: 35.
- World Health Organization. *International Classification of Diseases, 9th Revision, Clinical Modification* (Dutch Edition). Prismant: Utrecht 2003.
- Ditunno -JFJ, Young W, Donovan WH, Creasey G. The international standards booklet for neurological and functional classification of spinal cord injury. *Paraplegia* 1994; **32**: 70–80.
- Maynard FM et al. International standards for neurological and functional classification of spinal cord injury. *Spinal Cord* 1997; **35**: 266–274.
- Bailey RB. Urologic management of spina bifida. In: Rekate HL (ed). *Comprehensive Management of Spina Bifida*. CRC Press: Boca Raton 1991, pp 185–213.
- Raven J, Raven JC, Court JH. Raven manual: section 3. In: Raven J, Raven JC, Court JH (eds). *Manual for Raven's Progressive Matrices and Vocabulary Scales*. Oxford Psychologists Press: Oxford 1998.
- Bouma A, Mulder JL, Lindeboom J. *Neuropsychologische diagnostiek: Handboek*, Deel 1. Swets & Zeitlinger: Lisse 1996.
- Hoffer MM, Feiwell E, Perry R, Perry J, Bonnet C. Functional ambulation in patients with myelomeningocele. *J Bone Joint Surg Am* 1973; **55**: 137–148.
- Hunt GM, Poulton A. Open spina bifida: a complete cohort reviewed 25 years after closure. *Dev Med Child Neurol* 1995; **37**: 19–29.
- Sutherland RS, Mevorach RA, Baskin LS, Kogan BA. Spinal dysraphism in children: an overview and an approach to prevent complications. *Urology* 1995; **46**: 294–304.
- Kryger JV, Gonzalez R, Barthold JS. Surgical management of urinary incontinence in children with neurogenic sphincteric incompetence. *J Urol* 2000; **163**: 256–263.
- Ponticelli A, Iacobelli BD, Silveri M, Broggi G, Rivosecchi M, De-Gennaro M. Colorectal dysfunction and faecal incontinence in children with spina bifida. *Br J Urol* 1998; **81**(Suppl 3): 117–119.