

## A 30-YEAR FOLLOW-UP STUDY OF PATIENTS WITH OCCULT SPINAL DYSRAPHISM: BLADDER FUNCTION, URINARY INCONTINENCE, QUALITY OF LIFE, AND FERTILITY

### Aims of study

This is a first report which for a period of 30 years followed-up 25 patients with occult spinal dysraphism in respect of bladder function, urinary incontinence, quality of life (QoL), and fertility.

### Materials and methods

Through a retrospective chart review of 35 patients who visited authors and were treated at least 3 years, 25 patients consisting of 14 males and 11 females with a mean age of 43.4 (sd: 12.1) were identified and gave consent to provide information on their health conditions and marital status. The diagnosis of occult spinal dysraphism was based on clinical findings of cutaneous markers, video-urodynamics, myelography and/or MRI. The International Consultation on Incontinence Questionnaire-Short Form (ICIQ-SF) (1) was incorporated to evaluate severity of urinary incontinence (frequency and amount of leakage; score range 0 - 11) and QoL (score range 0 - 10).

### Results (Table)

Chief complaints comprised urinary incontinence in 16 patients, difficulty in urination in 5, bed wetting in 2, and soft tumor in the back in 2. Of the 25 patients 19 (76%) had urodynamically had detrusor underactivity, 4 (16%) detrusor overactivity and 2 were not tested. Skin stigmata of various shapes and sizes were observed on the lower back, along with urinary incontinence or foot deformities. A majority of the 25 patients have undergone multiple operations such as untethering surgery of the spinal cord in 17 patients, anti-reflux surgery 11, enterocystoplasty in 10, sling surgery in 8, surgeries for urolithiasis in 4, and various orthopaedic surgeries in 10 (mean of 4.2 per patient). The patients were divided into 3 groups according to voiding manoeuvres. Group I comprises 4 patients who have enjoyed normal bladder function, Group II consists of 18 patients who have been dependent on clean intermittent catheterization, and Group III includes 3 patients who have voided with the Valsalva manoeuvre. Severity of urinary incontinence was the slightest and QoL was normal in Group I (2 and 0.5, respectively), while severity of incontinence was the worst and QoL was significantly impaired in Group III (7.7 and 5.7, respectively). Group II was located in between the two. Eleven patients have married during the follow-up period, 2 had married prior to visiting us, and these 13 patients have had a total of 20 healthy children of their own.

### Interpretation of results

Four patients in Group I have enjoyed normal bladder function, which believes to be significantly correlated with the detrusor being overactive and untethering surgery being performed within 3 years following the onset of bladder symptoms (2). On the other hand, bladder function of 21 patients in Groups II and III was not so well preserved as those in Group I. Namely, their detrusor had been underactive, untethering surgery was attempted in 13 patients a mean of 7.9 years after the symptom onset, and enterocystoplasty had to be performed with or without fascia sling procedures at the bladder neck. Surgical outcomes of untethering surgery were not satisfactory in Group II and III as far as recovery of bladder function or acquisition of urinary continence are concerned. The fact that 13 of 25 patients (52%) have married and have had 20 healthy children demonstrates that fertility of those suffered occult spinal dysraphism has been much better than those with spinal dysraphism (3).

### Concluding message

It is concluded that early recognition of occult spinal dysraphism and untethering surgery prior to the loss of detrusor contractility are of prime importance, that since a majority of the patients have been annoyed with varying degrees of incontinence and deteriorated QoL, fascia sling together with surgical intervention at the bladder neck have to be meticulously executed for those with bladder neck incompetence, and that fertility of those with occult spinal dysraphism is probably the same as that of normal population.

Group, No. of pts M/F	Age and detrusor function at initial visit	Present voiding maneuver	ICIQ-SF Severity (range)	ICIQ-SF QoL (range)	Marital status	Follow-up years (range)
Group I 4 pts 0/4	5.8 yo Overactive 3 Unknown 1	normal	2 (0 - 4)	0.5 (0 - 1)	3 married 3 children	31 years (30 - 32)
Group II 18 pts 11/7	15.1 yo Underactive 17 Unknown 1	CIC	5.5 (0 - 9)	3.0 (0 - 7)	8 married 12 children	35 years (16 - 40)
Group III 3 pts 3/0	24.7 yo Underactive 3	Valsalva	7.7 (3 - 11)	5.7 (0 - 9)	2 married 5 children	33 years (28 - 43)
TOTAL 25 pts 14/11	13.2 yo Underactive 20 Overactive 3 Unknown 2		5.2 (0 - 11)	2.9 (0 - 9)	13 married 20 children	30 years (16 - 43)

#### References

1. Coyne K, et al.. Patient reported outcomes: the ICIQ and the state of the art. *Neurourol Urodyn* 2010; 29: 645-54.
2. Kondo A, et al. Bladder dysfunction secondary to tethered cord syndrome in adults: Is it curable? *J Urol* 1986; 135: 313-6.
3. Lassmann J, et al. Sexual function in adult patients with spina bifida and its impact on quality of life. *J Urol* 2007; 178: 1611-4.

#### Disclosures

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