THE ADULT SPINA BIFIDA PATIENT: DOES A DELAY IN REFERRAL IMPACT URODYANMIC FINDINGS AND CLINICAL OUTCOMES? RECOMMENDATIONS FOR TRANSITION OF CARE

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BACKGROUND

- **Spina bifida is a neurological disease characterized by the failure of the caudal neural tube to fuse during early development.**
- **30 per 100,000 births in the US are affected by spina bifida, and many have significant urologic issues.**
- **Historically, 1/3 of patients had a urologic cause lead to early mortality.[1]**
- **50-95% of patients born with spina bifida live to adulthood.**
- **Currently, the majority of living spina bifida patients are adults.[2]**

STUDY GOAL

To examine the relationship between the delay in urological follow-up and clinical outcomes in adult spina bifida patients

MATERIALS AND METHODS

- **An IRB approved prospectively maintained database tracking patients with neurological conditions that presented for urologic evaluation at a tertiary referral center since 2000 was used to identify patients.**
  - **Of the 1100 neurological patients in the database, 60 have a diagnosis of spina bifida, and 39 of the spina bifida patients had undergone a urodynamic study.**
- **Patients who had documented prior urologic evaluation were assessed for the interval to presentation (n=53).**
- **Data was collected from electronic medical record: demographic information, urodynamic studies, imaging studies, lab values, presenting symptom, and time interval between prior urological evaluation.**

Demographics	Total (%)
Sex	
Female	29 (48.3)
Male	31 (51.7)
Age at Presentation(mean±std.range)	33±13 (16-64)
Wheelchair Bound	39 (65.0)
Reason for First Appointment	
Symptomatic	45 (75.0)
Establish Care	15 (25.0)
Abnormal Renal Imaging Finding (n=48)	29 (60.4)
GFR < 60 at most recent visit (n=38)	6 (15.8)

Table 1. Demographic information observed in the 60 spina bifida patients. Abnormal Renal Imaging includes presence of stones, medical renal disease, and hydronephrosis.

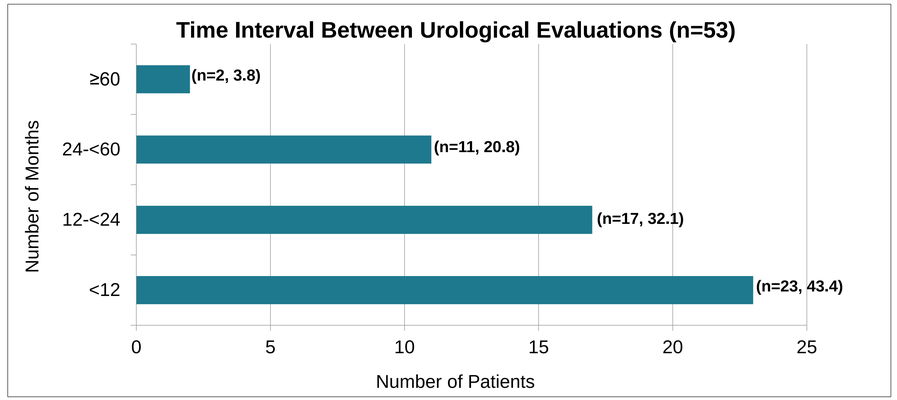

Figure 1. Time interval between initial tertiary Urology visit and prior Urologic evaluation.

Bladder Management	At Presentation (n=48)	At Last Visit (n=48)
Clean Intermittent Catheterization	19 (39.6)	23 (47.9)
Condom Catheter	2 (4.2)	1 (2.1)
Continent Urinary Diversion	10 (20.8)	12 (25.0)
Incontinent Urinary Diversion	2 (4.2)	2 (4.2)
Indwelling Suprapubic Catheter	1 (2.1)	2 (4.2)
Indwelling Urethral Catheter	5 (10.4)	3 (6.3)
Voiding	9 (18.8)	5 (10.4)
Medication Management	**At Presentation (n=48)**	**At Last Visit (n=48)**
Anticholinergic Medication	17 (35.4)	23 (47.9)

Table 2. Bladder and medication management at initial presentation and most recent visit. There was no significant change in either bladder or medication management between the two visits (p<0.0001).

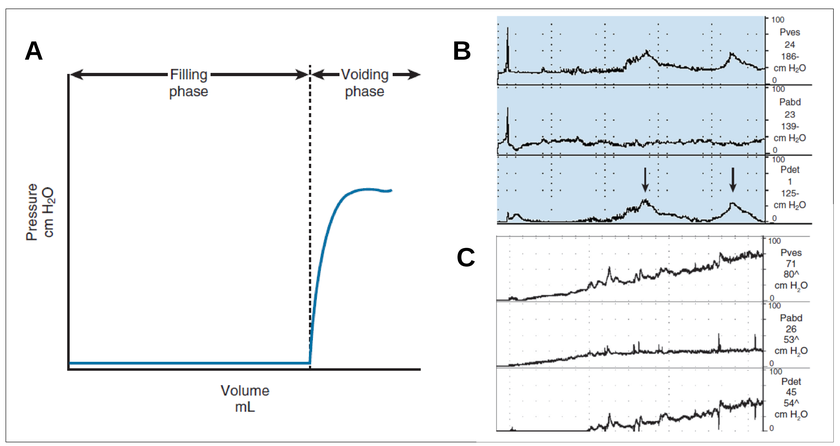

Figure 2. Examples of cystometrogram measurements of bladder pressure (cm H_20) over filling volume (mL). **A**, In a normal patient, the baseline bladder pressure is near zero and stays low until patient is given the command to void. **B,** In patients with detrusor overactivity, there are involuntary detrusor contractions (marked by the two arrows) indicated by a rise in Pves with no associated rise in Pabd. **C**, In patients with impaired compliance, a rise in Pves (and Pdet) is seen with filling.[3]
*Figure modified from Campbell-Walsh Urology, Figures 73-3, 73-4, and 73-5.

UDS Findings	>1 year (n = 15)	1-2 years (n = 11)	2-5 years (n = 7)	>5 years (n = 0)	*p*
Detrusor Overactivity	1 (6.7)	6 (54.5)	1 (14.3)	-	0.0215
DESD	2 (28.6)	0 (0.0)	1 (100.0)	-	0.5475
Decreased Compliance	6 (40.0)	4 (36.4)	4 (57.1)	-	0.7341

Table 3. Association between urodynamic findings and time interval between urologic evaluations.

RESULTS

- **The majority of patients presented for symptom evaluation (75%) vs. establishing care (25%).**
- **Patients were significantly more likely to present within 12 months of their last evaluation if they were symptomatic (p=0.022).**
- **The most common presenting symptoms were incontinence (n=18, 30%) and urinary tract infection (n=15, 25%).**
- **Patients presenting more than one year from their last evaluation were more likely to have detrusor overactivity (p=0.0215).**
- **Neither altered compliance nor detrusor external sphincter dyssynergia were associated with a delay in diagnosis.**
- **Impaired compliance was significantly associated with abnormal renal imaging findings (p=0.0328).**
- **42% of patients required intervention following referral.**
- **Urologic workup including a urodynamic study altered clinical management in 58.9% of patients.**

CONCLUSIONS

- **Spina Bifida patients continue to require close surveillance into adulthood, and this evaluation must include urodynamic testing.**
- **There is indication that patients who delay care are more likely to have UDS abnormalities that might necessitate changes in management strategies.**
- **We advocate follow-up of less than 12 months between adult urology clinics or within one year after pediatric surveillance has terminated.**

REFERENCES

1. Snow-Lisy, Devon C., Elizabeth B. Yerkes, and Earl Y. Cheng. "Update on Urological Management of Spina Bifida from Prenatal Diagnosis to Adulthood." *The Journal of Urology* 194.2 (2015): 288-96.
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3. Campbell, Meredith F., and Patrick C. Walsh. "Urodynamic and Video-Urodynamic Evaluation of the Lower Urinary Tract." Ed. Louis R. Kavoussi, Alan W. Partin, and Craig Peters. *Campbell-Walsh Urology*. Ed. Alan J. Wein. 11th ed. Philadelphia: Elsevier, 2016. 1718-742