Trends in Toilet Training and Voiding Habits among Children with Down Syndrome

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Purpose: Children with Down syndrome are at risk for lower urinary tract dysfunction and delayed toilet training. Comparative studies regarding voiding function in the Down syndrome population are lacking. We assessed urinary continence and voiding function in patients with Down syndrome and a control group.

Materials and Methods: A questionnaire designed to assess toilet training, continence status, symptoms of lower urinary tract dysfunction and prior evaluation of urological complaints was sent to parents of 326 children with Down syndrome who had been seen at our institution previously. The same survey was administered to parents of patients without Down syndrome. Data were compiled, and descriptive and comparative statistical analyses were performed.

Results: A total of 77 patients comprised the Down syndrome group and 78 patients without Down syndrome comprised the control group. Average age of reported toilet training completion was 5.5 years in children with Down syndrome and 2.2 years in controls. Of children 5 years or older 79% with Down syndrome were toilet trained, compared to 100% of those without Down syndrome. Incontinence was reported in 46% of previously toilet trained children with Down syndrome and 24.5% of controls. These findings were statistically significant. No significant difference was observed in the rate of urinary tract infection, symptoms of lower urinary tract dysfunction or evaluation for urological complaints.

Conclusions: Children with Down syndrome can experience marked delay in toilet training and are more likely to suffer incontinence afterward. This study was ineffective in determining whether symptoms of lower urinary tract dysfunction could be related to decreased continence rates.

Key Words: Down syndrome, lower urinary tract symptoms, toilet training, urinary incontinence

Abbreviations and Acronyms

CG = control group

DS = Down syndrome

LUTD = lower urinary tract dysfunction

UTI = urinary tract infection

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Down syndrome, trisomy of chromosome 21, occurs in 1 in 1,000 live births in the United States.[1] Nearly every organ system is affected to some degree, with early mortality linked to cardiac and gastrointestinal disorders.[2] Urological manifestations of Down syndrome are well described, and virtually all congenital urological conditions are represented via case reports.[3] In addition to anatomical anomalies, voiding dysfunction with resultant renal injury has been described in boys and is concerning

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for urologists who treat this population.[4] Prior research has suggested that some element of voiding dysfunction is present in 77% of patients with Down syndrome.[5]

Voiding function in children with DS is thought to correlate with overall cognitive function, although the ability to accurately assess what constitutes abnormal voiding is limited by a lack of normative data on continence rates in children with DS. We sought to expand the knowledge base regarding normal and abnormal voiding patterns in children with DS, comparing the data of interest to a control population. We hypothesized that children with DS experience a delay in attainment of volitional control of urine and experience more symptoms of voiding dysfunction than controls.

METHODS

We developed a parent centered questionnaire based on the work of Hicks et al, which was designed to assess a history of toilet training, incontinence after toilet training, symptoms of LUTD and any prior evaluation for urinary related conditions (supplementary Appendix, http://jurology.com/).[5] This questionnaire has not been externally validated. Our experimental population was derived from a database of children with DS seen at our institution for inpatient or outpatient services from 2000 to 2012. The only inclusion criterion for the group was DS as identified by ICD-9 code 758.0. This database included visits to the full spectrum of clinical specialists and was not specific to urology patients. The data were not further sorted by comorbidities or presenting complaints. No age criteria were instituted, although our institution generally does not care for patients beyond age 21 years without a medical exception. Questionnaires were mailed to the parents of these children. Nonresponders to the first mailing were again contacted via mailed questionnaire. No telephone contact with nonresponders was attempted.

Controls were obtained by administering the same questionnaire to parents of patients visiting the outpatient clinics at our institution (orthopedic, allergy/immunology, etc). Patients being seen by the urology, neurology and neurosurgery clinics were excluded. The CG questionnaire was administered in person by an institutional review board approved independent surveyor. A consecutive cohort of patients was obtained during a period of 1 month, and no parent who was offered the survey declined to participate. No age or gender matching was performed.

Symptoms of LUTD were considered to be present if the survey had at least 1 affirmative response on the items dealing with voiding ("problems emptying," "trouble starting," "weak urinary stream," "start and stop while peeing" and "greater than a day without peeing"). The intent of the survey was not to make a clinical diagnosis of defined entities such as dysfunctional voiding, but to serve as a generalized assessment of continence and voiding patterns in cases and controls.[6] Once completed, the data were compiled into a database, and descriptive and comparative statistical analyses were performed via Fisher exact test, Student t-test, and chi-square analysis using Excel® and GraphPad®, as indicated.

RESULTS

A total of 420 patients with DS presented to our institution between 2000 and 2012. All were mailed a questionnaire, of which 94 were returned for incorrect contact information. Of the remaining 326 patients 62 responded to the first mailing and an additional 15 responded to the second mailing. The response rate was 23.6% (77 of 326). Controls consisted of 78 consecutive children without DS whose parents completed the questionnaire in person.

Average age was 10.3 years (median 9.6, range 0.3 to 27.0) in patients with DS and 8.1 years (7.3, 1.3 to 18.5) in controls, which is a statistically significant difference. There was no statistical difference in percent males per group. In children with DS the average age of initial interest in toilet training was 3.8 years and the duration of toilet training was 1.9 years. In controls the average age of initial interest in toilet training was 1.8 years and duration of training was 0.5 years. Average age at completion of toilet training was 5.5 years (range 0.8 to 12.0) in the DS group and 2.2 years (0.8 to 4.5) in controls ($p < 0.01$). Of children younger than 5 years 18.8% in the DS group and 53.6% in the CG were toilet trained ($p = 0.03$). Of children 5 years or older 78.7% in the DS group and 100% in the CG were toilet trained ($p < 0.01$, table 1).

Incontinence in previously toilet trained children was reported in 46% of the DS group and 24.6% of the CG ($p = 0.02$, table 2). Average age of these children with accidental wetting was 11.1 years (range 4.7 to 19.4) in the DS group and 6.7 years (2.8 to 13.2) in the CG. Further evaluation in toilet trained children with incontinence was performed to assess for any difference in wetting patterns. Patients with DS had an equal distribution of children who wet during the day only, during the night only and in a diurnal pattern. Controls had an unequal distribution of incontinence, with most children experiencing nighttime wetting (see figure).

Respondents reported that UTIs occurred at a similar rate in both groups (21.1% in children with

Table 1

	DS Group	Controls	p Value
Mean yrs age (range)	10.3 (0.3–27.0)	8.1 (1.3–18.5)	0.01
No. male/total No. (%)	34/77 (44.1)	35/78 (44.9)	1.00
Mean yrs age at completion of toilet training (range)	5.5 (0.8–12.0)	2.2 (0.8–4.5)	<0.01
No. toilet trained/total No. (%):			
Younger than 5 yrs	3/16 (18.8)	15/28 (53.6)	0.03
5 Yrs or older	48/61 (78.7)	50/50 (100)	<0.01