

How to investigate the epidemiology and incidence of failed hypospadias repair in the United States

Chris M. Gonzalez MD MBA
Director of Genitourinary Reconstruction
Associate Professor
Department of Urology
Northwestern University
Chicago, Illinois

Pediatric Hypospadias Disease

- Hypospadias incidence is 1/250 to 1/300 live births (Baskin 2000)
 - Incidence and severity rising
 - Varied across regions in the United States
 - Etiology unclear
 - Genetic, developmental, endocrine, and environmental factors involved
 - Ethnic trends

Pediatric Hypospadias Disease

- Over 200 different repairs have been described
- Goals of treatment include:
 - Stand to void
 - Preserve sexual function
 - Cosmetic appearance
- Outcomes generally adequate
- Complications
 - Fistula, diverticulum, chordee, meatal stenosis, urethral stricture disease (6.5%)

Duel et al 1998

Pediatric Hypospadias Evaluation

- Outpatient visits
 - Physician office visits increased significantly from 1994 - 2002
429 to 655/100,000
 - Medicaid
 - Military
 - Uninsured
- National Hospital Ambulatory Medical Care Survey
 - 2002 18,78.00
 - 2003 19,471.00
 - 2004 4,930.00
 - 2005 10,343.00
 - 2006 37,447.00
 - 2007 12,582.00
 - 2008 23,871.00
- Medicaid
 - 160 / 100,000 annually
- Military
- Uninsured

(Pohl et al 2007, Miller et al 2009)

Pediatric Hypospadias Treatment

- National Survey of Ambulatory Surgery
 - 39,631 hypospadias repair cases (1994 – 1996)
 - 0-2 years 26,381 boys
 - 3-10 years 7,296 boys
 - 11-17 years 5,782 boys
- Ambulatory surgery for hypospadias has increased 1.5 fold from 1994 - 2002
 - 321 - 468/100,000
- Hospitalization rate increased in boys 11-17 years old undergoing hypospadias repair (1994 – 2000)
- Inpatient costs
 - 11-17 years old (\$5,716 / episode of care)
 - 18-29 years old (\$6,914 / episode of care) (Pohl et al 2007)

Adulthood Complications from Previous Hypospadias Repair

- Data are conflicting and sparse
 - Retrospective chart reviews and mail response questionnaires
 - Original location of the meatus and type of surgery missing or unknown
 - Patient motivation to cooperate
 - Surgeon and patient bias
 - No correlation between surgeon and patient perception after hypospadias surgery (Mureau et al)
 - Follow-up

Longer Term Follow-up

- Outcomes with oral mucosa for hypospadias repair
 - Fichtner et al 2004
 - Redo cases 27/49 (55%)
 - Average follow-up 6.2 years
 - Complication rate 24%
 - Fistula, stricture, graft contracture, meatal stenosis
 - Nelson et al 2005
 - Complex hypospadias disease
 - Mean study age 15 years
 - » Median follow-up 6.9 years
 - Urethral complications 22/43 (51%)
 - Required ≥ 1 procedure
 - Voiding complaints 23/43 (53%)
 - 51% satisfied with cosmetic appearance

Where to begin in the United States?

- **United States has a disjointed health care system**
 - Multiple employer and insurance databases
 - Government system
 - Medicare
 - Medicaid
 - Veterans Administration
 - Military
 - Uninsured
- **Electronic medical records**
 - Software systems with no connectivity
- **Patient migration**

Failed Hypospadias Repair

- Northwestern Memorial Hospital Enterprise Data Warehouse (EDW)
 - Group A
 - All men with hypospadias ICD – 9 code 752.0
 - 369 men (191 \leq 18 years old)
 - » 9 patients with CPT (procedure) code for hypospadias repair 54322 – 54332
 - Group B
 - ICD 9 codes for potential conditions involving hypospadias or following hypospadias surgery
 - Urethral stricture, fistula, urinary retention, sexual dysfunction
 - Psychiatric disorders (depression, anxiety, personality)
 - Substance abuse (drug, alcohol, smoking)

Failed Hypospadias Repair

- Northwestern Memorial Hospital EDW
 - Intersection of diagnoses between Groups A and B was 124/ 360 (34%) men
 - Urologic diagnoses
 - Urethral stricture 123/360 (34%)
 - UTI 32/360 (9%)
 - Disorder of the penis 71/360 (20%)
 - Lichen sclerosis (3.3%)
 - Psychiatric diagnoses (depression, anxiety)
 - 68/360 (19%)
 - Substance abuse low
 - Limitations
 - How many were repaired?
 - Causality
 - Relatively small pool

Nationwide Inpatient Sample

- Largest all-payer inpatient care database in the United States
 - Cross sectional analysis
 - 8 million admissions annually from over 1,000 hospitals between 2004 - 2007
 - 110,733 urethral stricture diagnosis
 - 97 (0.1%) co-diagnosis of hypospadias
 - 7,816 urethroplasty procedures
 - 50 (0.6%) had co-diagnosis of hypospadias
 - 548 patients with diagnosis of hypospadias
 - Analysis
 - Inpatient data
 - Reflection of treatment patterns?
 - Are these patients being treated with dilation or urethrotomy on outpatient basis?

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- Collaboration with the Agenzia Sanitaria Regionale of the Emilia-Romagna Region
 - Inpatient encounter-based records utilizing administrative data
 - Individual, geographic, and financial levels of analyses
 - Similar to United States NIS
 - Nine years of data 2002 - 2009
 - ICD 9 codes
 - ICD treatment codes
 - Hypospadias found in 2,183 male patients

Thomas Jefferson University

- Urethral stricture disease
 - 10,655 male patients
 - Only 77 patients with co-diagnoses of hypospadias and urethral stricture disease
- Patterns
 - 2,183 hypospadias diagnoses
 - 1,188 hypospadias repairs (55%)
 - Hospitalization rate is high
 - Large number of male patients without hypospadias repair code
 - Age stratification
 - Urethroplasty data

Kaiser Permanente

- Largest managed care organization in the US
- 8.6 million patient records
 - ICD 9 and 10 and CPT Codes
 - Complications
 - Mental conditions
 - Substance abuse
 - Urethral procedures
 - Limitations
 - Patient migration from insurance captive
 - Under reporting
 - CPT code for hypospadias repair not included if patient had surgery outside of Kaiser

Failed Hypospadias Repair

- Descriptive Analysis of 1176 Patients with Failed Hypospadias Repair (Barbagli et al 2010)
 - 250 (ages 1-16)
 - 451 (ages 17-20)
 - 358 (ages 21-40)
 - 112 (ages 41-60)
 - » Males > 16 years old 926/1176 (79%)
 - ***Nearly 60% of patients developed complications over the past 20 years***
 - **Worldwide burden?**

Future Directions

- Pediatric hypospadias disease incidence, severity, and treatment patterns increasing
- Single payer systems
- Website based registry
 - Evaluation tools
 - Links to regional centers of excellence
 - Multiple languages
- Impact of hypospadias repair and complications