

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

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# 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 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  $\geq 1$  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?

# Thomas Jefferson University

- 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