Spina Bifida: Complex Decision Points
Role of Urodynamics and CIC in Infants

Stacy T Tanaka MD MS
Professor, Urology
Medical Director, Spina Bifida Clinic
Monroe Carell Jr Children’s Hospital at Vanderbilt
Disclosures

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Prevent CKD: the “known knowns”

• Most born with normal kidneys
• Some at higher risk for renal deterioration
• Risk for renal deterioration is modifiable
Prevent CKD: the “known knowns”

• Most born with normal kidneys
  • Historical: 90-95% have normal urinary tract when first evaluated
  • Contemporary (UMPIRE):
    RBUS: 105/188 (SFU 0), 76/188 (SFU 1-2)
    DMSA: 61/66 no renal defects

Bauer SB 1985; Tanaka ST et al 2019
Prevent CKD: the “known knowns”

• Some at higher risk for renal deterioration
  • DSD
  • DLPP > 40 cm H$_2$O

McGuire EJ et al 1981; Bauer SB et al 1984
Prevent CKD: the “known knowns”

- Renal deterioration is modifiable
  - Historical: 695 adults since 1944
    - 56 deaths with known cause → 33% renal
  - Contemporary (2012): 1128 adults
    - Mean age 26y
    - CKD 26%
    - ESRD 1.3%

Singhal B & Mathew KM 1999; Veenboer PW et al 2012
Current proactive approach

Urodynamics as infant

High risk: DSD or DLPP>40

CIC + anticholinergic

Low risk
Urodynamics for risk stratification, but...

Dr. Noel Tulipan:
• Neurosurgeon pioneer – in utero MMC repair
• “Are the urodynamics bad?”
Urodymanics for risk stratification, but ...

Raw signal

Signal processing
Urodynamics for risk stratification, but...

- Subjective interpretation of known risk factors: DSD, DLPP and others
- Low interrater reliability

Dudley AG et al 2018
Consequences of imprecise measurements

- Harder to detect an actual difference

More precise

Less precise

Series 1 • Series 2
Differences in bladder function, but not urodynamics!

• Prenatal vs postnatal closure
• MOMS: Difference in voiding status
• Katowice: Better continence, fewer UTIs
• No difference in urodynamics

Brock JW et al 2019; Pastuszka A et al 2019 (ICCS abstract)
Possible conclusions

• Urodynamics are useless, OR
• Urodynamics could be better
Process to improve urodynamics

• UMPIRE: Urologic Management to Preserve Initial Renal Function for Young Children with Spina Bifida
• Baseline urodynamics < 4mo
• Initial studies: 5/2015–9/2017
Process to improve urodynamics
Process to improve urodynamics

9 clinical sites
- Interpret
- Refine definitions
- Re-interpret

Outside review
Chris Austin
Duong Tu
John Wiener
Elizabeth Yerkes

Re-refine definitions
How to (try to) improve urodynamics

2017-2019

Denial
Disbelief, looking for evidence that it isn’t true

Frustration
Recognition that things are different; sometimes angry

Shock
Surprise or shock at the event

Depression
Low mood, lacking in energy

Integration
Changes integrated; a renewed individual

Decision
Learning how to work in the new situation; feeling more positive

Experiment
Initial engagement with the new situation
How to (try to) improve urodynamics

Morale and Competence

Denial
Disbelief, looking for evidence that it isn’t true

Frustration
Recognition that things are different; sometimes angry

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Low mood; lacking in energy

Integrate
Changes integrated; a renewed individual

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June 2019
UMPIRE process to improve urodynamics

• All 3 reviewers agreed on overall bladder classification for only 58%
Process to improve urodynamics

Dr. Earl Cheng:

• “This is bad.”
• Convinced 6 other pediatric urologists to sit in a room for 2 days to review urodynamics
September 5-6, Chicago
How to (try to) improve urodynamics
Lessons learned

• Value of face-to-face communication
• September 5: Agreed on 80/135 (58%)
• September 6: Agreed on 108/158 (68%)
Lessons learned: problems of technique

• Fill rate
• Volume: To leak? To capacity? To pressure?
• # Cycles - best or worst cycle?
• Catheter in through void?
• Annotation
Lessons learned
problems of interpretation

• Definitions not good enough for real world tracings
  • Leak point pressure?
  • DSD?
  • DO?
Where to measure pressure?
Is it DSD?
Is it DSD? Or movement?
Is it DO?
Lessons learned - action item

• Well tempered urodynamics for infants/children with spina bifida
  • Standardize technique
  • Standardize interpretation

Conway JJ & Maizels M: Well tempered diuretic renogram, 1999
So why bother?

- In 20s
  - CKD rate 26%
  - Low ESRD rate
  - What about 30s, 40s?
- USRDS: average onset of ESRD in spina bifida = 41y

Ouyang L et al 2015; Veenboer PW et al 2012
Who needs CIC as an infant?

- UMPIRE indications for CIC + oxybutynin, OR
  - DLPP or end fill pressure > 40 cm H2O, and/or
  - DSD

- CIC + oxybutynin for everyone, OR

- Expand urodynamic indications for early intervention

“Good” and “bad” intermediates

Originally characterized as safe

Originally characterized as hostile

Intermediate | Safe
---|---

Hostile | Intermediate
Take home points

• Renal deterioration risk is modifiable
• Urodynamics important part of risk stratification
• In research studies, urodynamics only useful if technique and interpretation standardized