

Functional paediatric vs. adult urology - is there a need for a smooth transition?

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Disclosures

No relevant disclosures for this presentation

Introduction

Case:

- Boy
 - Spina bifida
 - Recurrent UTI's
- Comfortable with his doctor and specialized nurses/team

=> retires at patient age 44
- VUR, bladder low compliance
=> bladder augmentation + reimplantation ureters
 - Stable over the years
 - Social development: school, daily activities/social workplace, assisted living



Functional urology: paediatric

Examples:

- Urinary tract infections
- Monosymptomatic nocturnal enuresis
- Neurogenic bladder
- Vesicoureteric reflux
- Ureterocele / ectopic ureter
- Disorders/Differences in Sex Development
- Lower urinary tract obstruction



Functional urology: paediatric - adult

Examples:

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Functional urology: paediatric - adult

Congenital > Acquired

Functional urology: paediatric - adult

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Congenital anomalies:

- Resolved
- Chronic => Transition
- Delayed onset

Acquired

Adult functional urology

- What do we do differently?
 - Patient (more) in the lead
 - Interventions on outpatient clinic
 - (Life) longer follow up:
 - More stable
 - Less intense
 - Recognizing when it's going wrong => intervention
 - Concomitant (urological) comorbidity
 - Differences in structure, methods, reimbursements and culture
 - Urotherapy versus pelvic (floor muscles) training

Urotherapy

- Non-surgical
- Non-pharmacological
- Interventions for LUT malfunction
- Children & adolescents

Aim

Achieve normalization (or reduction) of the micturition and bowel pattern and to prevent further functional disturbance by repeated training.

A conservative-based therapy and treatment of LUT dysfunction that rehabilitates the LUT.

Secondary aims

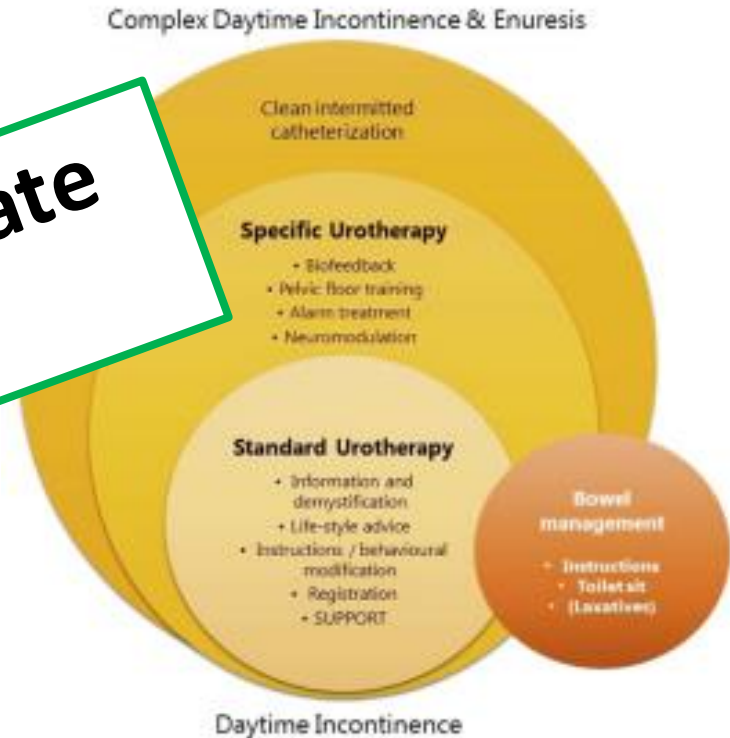
Improve:

- QoL children & parents/carers
- Skills to deal with symptoms & raising self-efficacy

Urotherapy

- Umbrella term
- Specialization
- Setting
- Standard urotherapy
- Specific urotherapy
- Integral approach
=> Cognitive behavioral psychotherapy

Child appropriate language



Transition

What is it?

- Case
 - Only the moment of transfer?
 - Only a good medical transfer between caregivers?
- The whole *proces* of transfer from child care to adult care
- Finish: patient is fully integrated in adult care or reached maturity.

Transition

- Timing?
 - When are patients ready?
 - Age / biological age / never?
 - Subject to many “transitions” in becoming an adult (maturity)
 - When are parents/carers ready?
 - When are caregivers ready?

For a smooth transition => start on time

- Independent living
- Further education
- Work
- Relationship

Be aware:

People with chronic disease,
more vulnerable to suboptimal
participation in society!

Transition

- NICE: transition from children's to adults' services for young people using health or social care services 2016, last update 2023.
- NL: Quality standard federation of medical specialist 2022 – Young people in transition from child care to adult care.

Transition

- We currently started in optimizing transition in functional urology (project Rotterdam University of applied sciences. Implementatie kwaliteitsstandaard).
- Optimizing timing?
 - Can Liesbeth help me out?
 - Can I help Liesbeth out?
 - Or actually, can we help out the patient together?

Transition

- Timing: age 12/13 – 25 years
- Coordinator
- Child-oriented and focus on a child's whole life
=> Individualized transition plan
- Self-management and participation
- Involvement of parents/carers and caregivers

Transition

To my opinion:

- Need for transition: a grading scale per patient
- Involvement of an adult urologist in “medical life events” of children with chronic disease
 - Development of skills
 - Familiarity with child/parents/carers

Transition of care

Statement:

- To enable a smooth transition, we need a “transition” of guidelines and how we work, e.g:
 - Having paediatric and adult functional urologist involved in both paediatric/adult guidelines development?
 - Lifelong guidelines for specific chronic congenital diseases?
 - ERN?
 - ...?

Take home message

- Child is subject to many transitions in developing maturity
- Adult care: patient (more) in the lead
- Caregivers: prevent lost to follow-up
- There's a need for a smooth transition!