ADOLESCENT & TRANSITIONAL UROLOGY

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ADOLESCENT UROLOGY

PRINCIPLES OF CARE

- Preservation of function (often requiring MD input)
- Medical and surgical treatment
- Self-caring of the patient
- Preparation for adult life (including sexual & reproductive function)

RENAL FUNCTION

Major Challenge to preserve renal function by:

-understanding findings that indicate renal deterioration

-knowing when nephrological support is needed

-deciding when surgery is indicated

RENAL FUNCTION

Development of end renal failure if not treated appropriately.

-Spina Bifida:
90% normal renal function at birth
End stage renal failure causes: 25% of childhood deaths
32% adulthood

-PUV:
32% suffer end renal failure by the age of 30 years.

RENAL FUNCTION

Deterioration of renal function starts with puberty (50%).

The evolution depends on:
-Albuminuria
-Number of febrile UTIs
-GFR at onset of deterioration (GFR 40: 70% chance)
-Hypertension

No sex related dominance

Urological re-evaluation to exclude mechanical obstruction

BLADDER FUNCTION

Adolescents treated in childhood for LUTD,
may still show abnormal/deteriorated bladder function.

Close corelation between bladder and kidney function.

Disturbed bladders may cause further renal damage.

BLADDER FUNCTION
PUV

-Typical for young children:

Low compliance, detrusor overactivity, reduced bladder capacity.

-Adolescence:

Valve bladder Syndrome

Nephrogenic diabetes insipidus, HUN, poor detrusor compliance, incontinence.

Urodynamic changes:

Decreasing overactivity, increasing capacity, decreasing contractility, chronic retention.

BLADDER FUNCTION
SPINA BIFIDA

Neurogenic bladder with detrusor-sphincter dyssynergia.

Detrusor function tends to deteriorate with onset of puberty.

Increasing cystometric capacity, Pdet max, leak point pressure -> secondary HN/VUR -> impaired renal function.

? Tethered cord

BLADDER FUNCTION
SPINA BIFIDA

Close FU:

Urodynamics
USS KUB
Renal Function
Control of management (anticholinergics, Botox, CIC)
Augmentation +/- catheterizable channel

SEXUALITY & FERTILITY

-Undescended Testis

-Disorders of sex development

-Bladder Exstrophy- Epispadias

-Hypospadias

-Spina bifida

SEXUALITY & FERTILITY
UDT

Cryptorchidism leads to compromised spermatogenic function.

Fertility is reduced in bilateral cryptorchid men.

Orchidopexy after puberty:

-predictive of decreased spermatic function.

-2-6x higher risk for testicular neoplasm.

SEXUALITY & FERTILITY
DSD

Patients disappointed with their genital image.

Correct guidance by the adolescent urologist regarding
urogenital function and appearance and
psychosocial counceling
necessary to avoid misconceptions & false expectations.

SEXUALITY & FERTILITY
BLADDER EXSTROPHY

Patients may experience issues with sexual function.

Fertility can be abnormal in males (multifactorial)

but usually not impaired in girls.

SEXUALITY & FERTILITY
HYPOSPADIAS

-Dissatisfaction with penile appearance (50%)

-Higher incidence of lower urinary tract symptoms.

SEXUALITY & FERTILITY
SPINA BIFIDA

Patients often fail to develop normal sexual activity.

Lack of privacy/ bladder&bowel control

Sexual function depends on the level of the lesion.

Females: normal fertility, males: abnormal.

TRANSITIONAL UROLOGY

KEYPOINTS

- More individuals with congenital urologic issues living and thriving into adulthood.

- Urologic goals of management include:
  -maintaining function of the upper tracts,
  -achieving continence,
  -minimizing infections,
  -improving sexual function, maximizing fertility potential, and
  -optimizing overall quality of life.

- continued care with an adult urologist beyond the paediatric period is helpful in ensuring lifelong urologic health.
- Much work remains to be done to understand the optimal pathways for transitioning patients to adult providers.

THE TRANSITION PROCESS

Aim:

To support the children/adolescents as they prepare to care for themselves independently.

Research has shown that :

quality of life and appropriate management of the underlying condition in later life are dependent on a smooth transition between paediatric and adult care providers.

To this point,

an optimal strategy has yet to be developed;

therefore, transition remains a highly individualized process.

TIMING OF TRANSITION

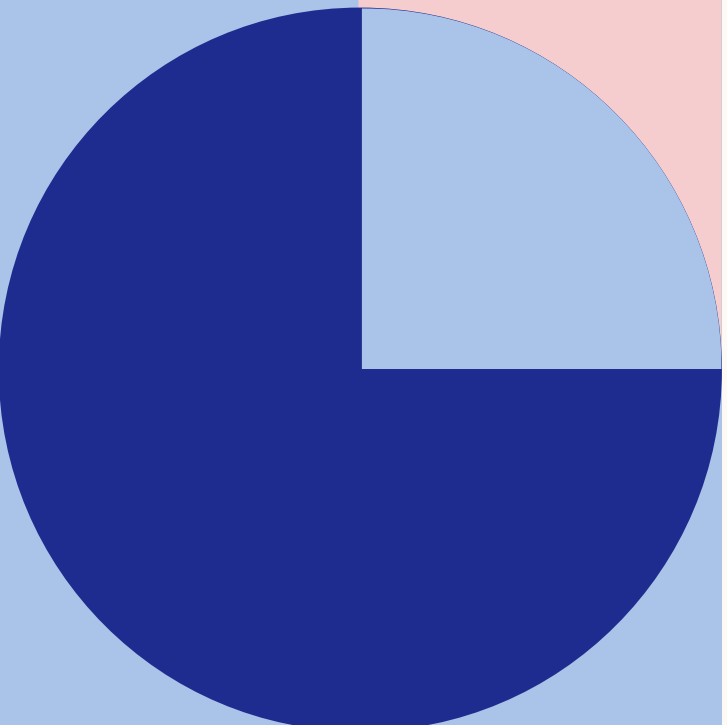
Optimal age: not established , needs to be individualized.

Factors as the patient's emotional maturity, family support, and current health status affect their readiness for a major shift in their care.

Failure to adequately prepare a patient for transition:
increases the risk of disengagement, poor treatment adherence, increased hospitalization rates and worse health outcomes.
Detrimental effects on future education and employment .

The ultimate marker of a successful transition is:
integration into adult society.

FACTORS AFFECTING TRANSITION



Riley Hospital for children:

The only factor that showed a trend toward improved transfer was the number of clinic appointments in the paediatric clinic over the 3 years leading up to transition

(although this did not reach statistical significance).

Other factors:

race, age at transition, insurance coverage, distance, prior medical and surgical history,

were not associated with successful transition.

FACTORS AFFECTING TRANSITION

Table 1 Key differences between paediatric and adult care.

Feature	Paediatric care	Adult care
Patient management	Involvement of a large multidisciplinary team, often lead by a single provider (referrals within the team)	Smaller teams with subspecialty expertise (referrals to other specialties as needed)
Care approach	Family centred	Patient centred
Patient functioning	Limited independence	Expected independence
Clinic management	Time allotted for detailed discussion with intensive coordination	Usually shorter appointment times and focused care coordination
Access to psychology	Good access	Often limited access
Follow-up	Regular active follow-up	More passive follow-up

Barriers in transitioning urologic patients from paediatric to adult care. Hoebeke et al

BARRIERS TO TRANSITION

PRACTITIONER-RELATED FACTORS

The paediatric urologist is ultimately the gatekeeper of the transition.

Certain level of comfort with the adult provider/institution necessary, to provide the endorsement to begin a trusting relationship.

Identifying an adult provider with the requisite knowledge, ability, and willingness to assume the care of complex cases is important.

Many adult providers lack specialized training in the conditions faced by patients with congenital issues.

(Some exposure during training, formal fellowship programs are limited).

BARRIERS TO TRANSITION
INSTITUTIONAL FACTORS

Adult facilities poorly equipped to handle the needs of patients with congenital issues. (lack of equipment/ latex-free environment).

Lack of multidisciplinary clinics.

Dedicated social work short in supply.

Many paediatric urology clinics do not have dedicated systems in place to ensure transition of care or appropriate follow-up when social conditions change.

BARRIERS TO TRANSITION

SYSTEM FACTORS

In countries without a universal health system, lack of insurance coverage is a significant detriment to transition of care.

Insurance coverage can become unaffordable.

This limits the ability to see providers for preventative health visits, forcing patients to delay seeking care until problems progress significantly in severity or acuity.

BARRIERS TO TRANSITION

PATIENT-RELATED FACTORS

Strong personal connections cannot easily be replaced.

Concerns that the new provider will not understand the complexity of their medical history.

Quick to detect teams who do not have an expertise that they are familiar with.

LOST IN TRANSITION

PATIENT-IDENTIFIED BARRIERS TO ADULT UROLOGICAL SPINA BIFIDA CARE.

D HETTEL , C.TRAN , K. SZYMANSKI, R. MISSERI , H.WOOD

Table 2 Responses at initial visit.

Question	Response: Yes	Subcategory	% Total (Yes)
Provider factors			
The drive was too far	4/27 (15%)	Location	7% (4/54)
The doctor I saw didn't understand my condition so I didn't go back	2/27 (7%)	Knowledge	4% (2/54)
The doctor I saw didn't understand me so I didn't go back	1/27 (4%)	Communication	26% (14/54)
I was never told I needed to see a new doctor	3/27 (11%)	Communication	
My old doctor just let me go	4/27 (15%)	Communication	
I was never referred to a new doctor	6/27 (22%)	Communication	
Patient factors			
I don't think of myself as an adult so why should I see an adult specialist	1/27 (4%)	Education	9% (5/54)
I didn't have any problems so I didn't go	2/27 (7%)	Education	
I didn't know I needed to be seen by a specialist after I "grew up"	2/27 (7%)	Education	
I didn't like the doctor I was sent to	1/27 (4%)	Preference	30% (16/54)
I was feeling fine	8/27 (30%)	Preference	
I am tired of seeing doctors	4/27 (15%)	Preference	
I have to see too many doctors	3/27 (11%)	Preference	
I forgot to go	0/25 (0%)	SMS	13% (7/54)
I moved away for college, job, other	2/27 (7%)	SMS	
I didn't know where/how to find a new doctor	4/27 (15%)	SMS	
I was too busy	1/27 (4%)	SMS	
I didn't have a way to get to the appointment	0/27 (0%)	SMS	
I don't have enough help with navigating the medical system	0/27 (0%)	SMS	
My family is less involved in my care	0/27 (0%)	SMS	
System factors			
I don't have insurance	4/27 (15%)	Insurance	11% (6/54)
My insurance was not accepted	2/27 (7%)	Insurance	

SMS = self-management/support.

PRINCIPLES

CONSESUS STATEMENT: AMERICAN ACADEMY OF PAEDIATRICS, AMERICAN ACADEMY OF FAMILY PRACTICE AND AMERICAN COLLEGE OF PHYSICIANS.

1. The importance of a youth- and/or young adult–centered, strength-based focus
2. Emphasis on self-determination, self-management, and family and/or caregiver engagement
3. Acknowledgment of individual differences and complexities on multiple levels
4. The recognition of vulnerabilities and need for a distinct population health approach for youth and young adults
5. The need for early and ongoing preparation, including the integration into an adult model of care
6. The importance of shared accountability, effective communication, and care coordination between pediatric and adult clinicians and systems of care
7. Recognition of the influences of cultural beliefs and attitudes as well as socio-economic status
8. Emphasis on achieving health equity and elimination of disparities
9. The need for parents and caregivers to support youth and young adults in building knowledge regarding their own health, skills in making health related decisions and using health care

EFFECTS OF PREVIOUS CLINICAL MODELS

Timberlake et al.:
59.6% of patients with chronic urological conditions
did not successfully transition to adult care
despite their efforts to define an extensive transitional care plan and graduation criteria for transfer into their adult system.

Szymanski et al. :
nearly 60% of their neurogenic bladder patients attending the transition clinic
did not adequately transition to an adult provider.

-Timberlake MD, Corbett ST, Costabile RA, Herndon CDA.
Identification of adolescent and adult patients receiving pediatric urologic care and establishment of a dedicated transition clinic. J Pediatr Urol 2015;11:62. e1e6.
-Szymanski KM, Cain MP, Hardacker TJ, Misseri R. How successful is the transition to adult urology care in spina bifida? A single center 7-year experience. J Pediatr Urol 2017;13: 40.e1e6.

EFFECTS OF PREVIOUS CLINICAL MODELS

1) Before I left the hospital, the staff and I agreed about clear health goals for me and how these would be reached.
2) The hospital staff took my preferences and those of my family or caregiver into account in deciding what my health care needs would be when I left the hospital.
3) The hospital staff took my preferences and those of my family or caregiver into account in deciding where my health care needs would be met when I left the hospital.
4) When I left the hospital, I had all the information I needed to be able to take care of myself.
5) When I left the hospital, I clearly understood how to manage my health.
6) When I left the hospital, I clearly understood the warning signs and symptoms I should watch for to monitor my health condition.
7) When I left the hospital, I had a readable and easily understood plan that described how all of my health care needs were going to be met.
8) When I left the hospital, I had a good understanding of my health condition and what makes it better or worse.
9) When I left the hospital, I had a good understanding of the things I was responsible for in managing my health.
10) When I left the hospital, I was confident that I knew what to do to manage my health.
11) When I left the hospital, I was confident I could actually do the things I needed to do to take care of my health.
12) When I left the hospital, I had a good understanding of the appointments or tests I needed to complete within the next months.
13) When I left the hospital, I clearly understood the purpose for taking each of my medications.
14) When I left the hospital, I clearly understood how to take each of my medications, including how much I should take and when.
15) When I left the hospital, I clearly understood the possible side effects of each of my medications.

Each answer was graded from 1 to 5 as follow:

1) strongly disagree 2) disagree 3) agree 4) Strongly agree
5) Don't know/Don't remember/Not applicable

Figure 1 The CTM-15 validated questionnaire.

Journal of Pediatric Urology (2015) 11, 89.e1–89.e5

Assessment of the introduction of an adolescent transition urology clinic using a validated questionnaire☆

Mohamed Sameh Shalaby [a,c], Anthony Gibson [a], Paraskeve Granitsiotis [b], Graeme Conn [b], Salvatore Cascio [a]

-87% of patients with various chronic urological conditions successfully transitioned to adult care.

-high satisfaction rate among those that transitioned using the CTM-15 (Care Transition Measure-15)questionnaire.

-Clinic every 6 months
-Mean age: 16 years
-paediatric and adult urologist, a urological nurse and, if needed, adolescent gynecologist.

IMPROVEMENT PROPOSALS

-The preparation of children by helping them obtain autonomy, independence, self-determination and self-advocacy should be initiated well before the intensive transition period.

-Discussions about transition and the actual transitions themselves should not be made during a time of crisis.

-need for multidisciplinary adult care teams composed according to the congenital disease.

-The young person itself and not their disorder should be the center of attention of this team.

IMPROVEMENT PROPOSALS

Journal of Pediatric Urology (2021) 17, 144–152

Review Article

Barriers in transitioning urologic patients from pediatric to adult care

Wietse Claeys [a,c,*], Joshua D. Roth [a,b], Piet Hoebeke [a,c]

Potential solutions to barriers in transition

- Investment in networks and multidisciplinary teams with specific interest and knowledge of the pathologies at hand will lead to a more successful transition with less adverse effects.
- Investment in health insurance plans that can accommodate these patients with chronic care needs will lead to better patient follow-up and decrease emergency visits.
- Although a basic framework can form the start of a model for a care transition clinic, no single model will be suited for all clinical conditions and flexibility from providers is required.
- After transition, the primary care provider can play a pivotal role.
- The importance of sexual health in adolescents with chronic urological care needs has been underestimated.
- Transition should occur at the patient's pace.

TO CONCLUDE..

-Patients with congenital urologic anomalies have often had complex care that requires coordinated lifelong management.

-The move from paediatric to adult care is difficult for a variety of reasons.

-Transitional urology seeks to improve the care of these patients as they enter adulthood. It also offers the opportunity to further investigate the long-term outcomes of paediatric interventions.

-Much work lies ahead to define optimal pathways of care to improve the process of transitioning patient care and to optimize patient outcomes over time.

THANK YOU