No disclosures
No conflict of Interest
OBJECTIVES

- Understand Health Care Transition from Pediatric to Adult Health Care
- What are the Barriers to Transition
- Where is Peds-Adult Urology in Transition
- ? State of Art or State of Void ?
When the Pediatric Bladder is a Ticking Bomb

ADVANCES IN UROLOGY MEETING 2015
Tic Tock
PEDS SURGICAL GOALS

- PRESERVE & IMPROVE QUALITY of LIFE
- PRESERVE RENAL FUNCTION
- MAXIMIZE BLADDER FUNCTION
- OBTAIN FECAL & URINE CONTINENCE
- CREATE INDEPENDENCE

- TRANSITIONAL CARE
“I suppose I’ll be the one to mention the elephant in the room.”
A process for ensuring that high quality, developmentally appropriate health care services are available in an uninterrupted manner as a patient moves from adolescence to adulthood.
TRANSITION

• Adolescents need Transition care in all aspects of life
• Transition does not only involve Healthcare
• Managing medication, physicians, knowledge of medical condition, hospitals, medical resources
• Independent Living
• Education
• Vocation
• Insurance Coverage
• Community Inclusion
• Sexuality
• Transition > 18 million Adolescents 18-21 yrs
• 4.5 million (20%) have special needs/chronic conditions
• 20% account for 80% of Health Care Costs $$$$$
• >85% Report Lack of Access to Providers
• Only seek Healthcare Emergently/Admission
• Highest ER visit rate patients <75 yrs
• Most Patients, Families, Physicians, Hospitals and Health Care Systems are not prepared for TRANSITION

Prior et al. Pediatrics 2014
Transition is a growing/aging phenomenon

- Advances in treatment of chronic conditions, pharmacology, surgical techniques, medical technology, health care delivery system changes

- In Urology most identified Spina Bifida population as Adults with NEW & CONTINUED GU ISSUES

- In MMK 50% Hospital Admissions Preventable

- Estimated cost 360M/2yr

Kinsman, SL 1996/ Dicianno, BE 2010

15 YEAR OLD FEMALE HISTORY BLADDER EXSTROPHY BORN IN RUSSIA HAD CYSTECTOMY AND URETEROSIGMOIDOSTOMY.

HISTORY CKD, RTA, INCONTINECE URINE/STOOL, PROLAPSE
“GOT TRANSITION”

15 YEAR OLD FEMALE HISTORY BLADDER EXSTROPHY BORN IN RUSSIA HAD CYSTECTOMY AND URETEROSIGMOIDOSTOMY.

AGE 15 (2007) ORTHOPEDIC OSTEOTOMY/FIXATION, GU CONTINENT ILEOCECAL DIVERSION/TAKEDOWN URETEROSIGMOIDOSTOMY, APPENDIX/MITROFANOFF, RIGHT TO LEFT TRANSURETEROURETEROSTOMY, EXCISION VAGINAL DUPLICATION, VAGINAL SUSPENSION AND GENITOPLASTY.
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15 YEAR OLD FEMALE HISTORY BLADDER EXSTROPHY BORN IN RUSSIA HAD CYSTECTOMY AND URETEROSIGMOIDOSTOMY.

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AGE 25 (2016) PATIENT LIVING IN BOSTON PRESENTS TO ER MULTIPLE TIMES WITH DIFFICULTY CATHETERIZING MITROFANOFF, CHRONIC/ACUTE ABDOMINAL PAIN, HEMATURIA, FEVER AND EMESIS. GIVEN ANTIBIOTICS. NO TRANSITION.
“Before I leave my position, I would like to recall one major issue in the care of special children which has not been adequately addressed and which is a significant barrier to our adolescent and young adult population as they pursue independence. That is the barriers they encounter and must surmount if they are to secure ongoing quality medical care as they make that transition from childhood to adulthood.”
March 14, 1989 – presentation at Surgeons General Conference on Transition of Children with Special HealthCare needs to Adult Care
CONSENSUS STATEMENT 2002

- American Academy Pediatrics (AAP)
- American Academy Family Physicians (AAFP)
- American College Physicians (ACP)
- Transition process should begin by age 12yr
- Developmental readiness is better indicator than age
- Physician goals to Understand rationale, knowledge and skills to facilitate Transition
- Consensus statement 2002, Policy published 2011
- NHCTC established Six Core Elements of Transition

Pediatrics., 2002
McManus et al. Journal of Adol Health. 56:73, 2014
WHERE is HEALTH CARE TRANSITION

- Health care Transition is an unfulfilled promise
- Current literature is in form of Position and Consensus Statements, Recommendations, and suggested Transitional Process Elements
- NO Data, NO Research
- Outcomes conducted through Surveys and small samples from a few sub-specialty clinics and hospital programs

Current Opinion Care of Mature Pediatric Urology

• Practice pattern Questionnaire (62/200 peds urologists)
• Complex GU patients (MMC, Exstrophy, Cloaca, PUV, DSD)
• Adult urologists should follow adult patients
• Only 6.5% recommended Adult Care for Complex GU
• > 80% recommend care by a peds urologist or Adult urologist with training in Adolescent/Transition
• No Data, Research, Outcomes, Recommendations or Mechanism to provide Transitional Care

TRANSITION BARRIERS

• Medical Education Gaps at every level (UGME, GME, MOC)
• HCT implies Smooth transition but typically Abrupt
• Transition AGE related/restricted without preparation
• Lack of Communication, Coordination between Pediatric-Adult Care Providers
• Practice Differences between peds supportive family centered to Adult Independence
• Access Restrictions (Too Old, Too Complex)
• Patients psychosocial fears, new team, complexity
# Medical Education Training Transition

<table>
<thead>
<tr>
<th>Level Training</th>
<th>Adolescent Medicine</th>
<th>Care Handoffs</th>
<th>Complex Chronic Care</th>
<th>Transition Care</th>
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<td></td>
<td></td>
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<tr>
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<td>Internal Med</td>
<td>Exposure</td>
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<td>Yes</td>
<td>No</td>
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<td>Yes</td>
<td>No</td>
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<td>MOC</td>
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<tr>
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<tr>
<td>Family Med</td>
<td>Yes</td>
<td>No</td>
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</tbody>
</table>

UME = undergraduate medical education; GME = graduate medical education; MOC = maintenance of certification
MEDICAL EDUCATION & TRANSITION

- Training in chronic disease and Transition is not adequately addressed during residency
- At Subspecialty level NEED for enhanced training in Transition care for Fellowships
- Medical Knowledge competencies in chronic and congenital diseases, disability and transition for physicians already in practice.
- Transition training for physicians and all allied health care providers (nurses, NP, PA, psychologist, social workers)

BARRIERS

- Cherry-Picking and Lemon-Dropping Patients?
- Surgeons more likely (Urologists 31%)
- Physician’s lack of expertise or needed resources
- Bundling is a risk, payments based on outcomes
- Higher acuity patients with Poorer-paying insurances
- Health Report Cards at Risk (High Acuity Patients)
- Fear of Reporting Systems (PQRS, MIPS, MACRA)

Medscape, Feb 15, 2017
HOSPITAL BARRIERS

• Medical systems categorize patients as “PEDIATRIC or ADULT” based on age?
• More relevant category should be WHICH MEDICAL SETTING & PROVIDERS would provide best care for patient
• Hospital medical systems create false labels and blurr lines of care between Peds-Adult Transition
INSURANCE BARRIERS

• Insurance Companies Wary of uncertain future, untested, unbalanced risk pool
• Too much money for too few patients
• Driving up Costs
• Decrease Profits
• Increase Premiums
• Pull out of Markets
• Humana, United Healthcare, Aetna
• Less Insurers to choose
• Basic Problem with ACA/ObamaCare – TrumpCare ??
HHS Health Policy

- Triple goal US Health Care System
- Improve the Experience of Care
- Improve the Health of Populations
- Reduce per-capita costs of healthcare
- Replace MSGR and volume based reimbursement formula with Value-based reimbursement system
QPP, PQRS, MIPS, APM, VBM, MACRA
More and more physicians and health systems are treating patients less and less.
Rubric “Less is More”
Rethinking outdated practices to more effective evidence based “right care”
Reimbursement based on value not volume
Does this apply in Transitional Complex care??
“Less is More” or Transition “More is Less”
“Wow, excellent turnout.”
HEALTH CARE POLICY

RECOMMENDATIONS

• Percentage of Uninsured has decreased from 11% to 3.5% in 2010 as result of ACA
• Affordable Care Act (ACA) 2010 extending and mandating benefits
• ACA fosters improved coordinated care with evolution of accountable care organizations (ACO) as opportunity to address transition needs
• Financial payments/reimbursement CPT code changes for transition
• Transition services billing code changes for ICD-10
• Incentivize and build meaningful use (MU) protocols into healthcare transition such as providing medical clinical summaries
• Allow Simultaneous Peds & Adult billing during Transition of Care
• Financially Incentivize Providers for Transition Service

TRANSITIONAL UROLOGY

- 2015 Recommendations AUA Working Group
- Coined Term “Congenitalism”
- Index patient discussion management of adult case
- SPINA BIFIDA, EXSTROPHY
- Lack of Data, Management Complex, Need more Consensus discussions and recommendations throughout the life of these patients

Research Needs for Effective Transition in Lifelong Care of Congenital Genitourinary Conditions

February 2, 2015
CONSENSUS PANEL WORKING GROUP

“CONGENITALISM”
CONGENITALISM FORUM AUA 2016

- 165 participants AUA San Diego 2016
- 60% Pediatric Urologists
- 12% Reconstructive Urologists
- 10% Female Urologists
- 1% General Adult Urologists
- 17% Other (Fellows, residents, extenders, research)
- SB Persistent Incontinence, Augment/CKD/Sexuality
• Spina Bifida
  • Hypospadias/Epispadias
  • Disorders of Sexual Differentiation
  • Posterior Urethral Valves
  • Exstrophy, Cloaca
  • Prune Belly Syndrome
  • Cancer Survival
  • UTI, Incontinence Urine/Fecal
  • CKD, Upper tract deterioration, Transplantation
  • Complications of reconstructive bladder surgery
  • Sexual Function
  • Fertility/ Pregnancy
<table>
<thead>
<tr>
<th>Congenital Urologic Disease</th>
<th>Incidence</th>
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<tr>
<td>Spina Bifida: 7/10,000</td>
<td>2765</td>
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<tr>
<td>Exstrophy: 3/100,000</td>
<td>118</td>
</tr>
<tr>
<td>PUValves: 1/8000</td>
<td>493</td>
</tr>
<tr>
<td>Anorectal: 1/5000</td>
<td>790</td>
</tr>
<tr>
<td>Cloacal: 1/20,000</td>
<td>197</td>
</tr>
<tr>
<td>Prune Belly: 1/40,000</td>
<td>99</td>
</tr>
<tr>
<td>Dis Sex Dev: 1/5000</td>
<td>790</td>
</tr>
</tbody>
</table>

Total annual: 5252 cases

Adult Spina Bifida

- Antibiotics (40’s) / VP shunts (50’s) / CIC (70’s)
- > 90% patients today with MMK survive to Adulthood
- Incidence MMK decreasing but prevalence increasing
- MMK study 117 patients from 1963-1971
- 117 patients
- >50% Mortality by age 35yr
- >35% Deaths from ESRD
- > 55% Incontinent Fecal
- > 65% Incontinent Urine
- > 70% changes in Bladder Management as Adults
- > 40% needed Surgery

Martinez, LM.: Transition of Care for Adults with Congenital Urological Conditions. Curr Treat Options Peds (2016)

Szymanski, KM.: All Incontinence is Not Created Equal: Impact of Urinary and Fecal Incontinence on Quality of life in Adults with Spina Bifida. J Ped Urol. 2017

Chan, R.: The Fate of transitional Urology Patients Referred to a Tertiary Transitional Care Center. Urol. 2014
Mortality in SB patients has improved
>90% Survival Adult Age
Mortality form ESRD (0.5%)
Historic Data 50%
Mortality in SB is Non-Urologic Infections
### Transitional GU Concerns

<table>
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<td>Kidney Function/CKD</td>
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<td>Metabolic Disorders</td>
<td>Pregnancy</td>
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<td>Perforation</td>
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</tr>
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<td>Malignancy</td>
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</tr>
</tbody>
</table>
National Spina Bifida Registry

- Joint effort of the SBA, SBCCN & CDC (2014)
- 14 CDC funded / 7 self-funded clinics
- 8,000 patients
- Collect data and define practice outcomes
- Data: PSH, Urine/Fecal Continence, Mobility, Insurance, Education, Employment
- “Stool & School” = 6 x Employment
- Longitudinal Data review
- EMR based
- Develop Guidelines/Focus on Transition & Adult needs
- Future Research
TRANSITIONAL ELEMENTS

- Preparation/Resources
- Flexible Timing (age vs development)
- Care Coordination
- Development of Transitional Clinic
- Interested Health Care Providers
- “If you fail to plan, then you plan to fail”

Hospital commitment – Shannon Bevans has been hired 24 hours/week, dedicated to Adult Transition Program. SBACFL presented Orlando Health $20,000 resources for this effort in November 2016.
ADVICE FOR Transition Gروops

'Cos it's not all a bed of roses
“GOT TRANSITION”

24 year old male with history Exstrophy, Epispadias, Staged repair and Appendicovesicostomy.

Bladder managed with CIC three times day and voiding with Valsalva. Patient is sexually active. History of ED from penile angulation and of course SIZE.
“GOT TRANSITION”

- 18 year old obese female 11beta hydroxylase CAH with history high Urogenital sinus anomaly and PSARVP performed age 11 years. Normal voiding and menstruation with vaginal stenosis.

- Gynecology vaginal dilation under anesthesia with iatrogenic urethral vaginal fistula and postop urine incontinence.

- Vaginal Stenosis and complete urethral vaginal fistula
• 24 year old male with closed cloacal exstrophy variant on perineum with complete penoscrotal transposition, genital reconstruction, left nephrectomy non-function and ureteral ectopia into left seminal vesicle, ileocystoplasty, bladder neck closure and appendicovesicostomy.

• Presents > 1 year history of intermittent mucoid discharge from urethra and recent pain and swelling beneath the left penoscrotal area. Treated with course of Ciprofloxacin in ER and referred to Urology.
MAIZE MAZE
IT'S CORN-FUSING
Who should Care for patient?

1) General Adult Urologist
2) Reconstructive Urologist
3) Sexual Medicine
4) Pediatric Urologist
5) Urogynecologist
6) Transition Urologist
Spina Bifida Clinic Registry
MODEL for CARE TRANSITION

- Health and Human Services & National Alliance to Advance Adolescent Health Policy Statement to improve transitional care
- Adaptation of “SIX” Core Elements for “Got Transition”
  - (1) Develop practice-specific transition policy
  - (2) Establish Criteria to identify patients ready for transition
  - (3) Assess transition readiness beginning at age 14
  - (4) Transition planning: Identify adult providers, insurance resources
  - (5) Transfer of Care in period of stability
  - (6) Transfer Completion: Peds – Adult feedback
THE PEACEFUL TRANSFER OF...
Family-Centered Care Assessment

- Shared Decision-Making
- Health Promotion
- Strengths-Based Care
- Family Engagement
- Communication
- Care Coordination
- Cultural Competence
- Care Setting Practices

Group of people connected by lines, indicating interaction and collaboration.