Transition of Care From Pediatric to Adult GI

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Pediatric Gastroenterology
Objectives

- Pediatric vs Adult care model
- Important Aspects Of Transition
  - Timing
  - Barriers
  - Useful tools
- Recommendations for both Pediatric and Adult clinicians
Pediatric GI diseases

- Inflammatory Bowel Disease (IBD): >25% cases now diagnosed under 16yrs
- Celiac disease: Affects about 1% of population
- Eosinophilic Esophagitis: Incidence rising (~ 1/2500 individuals)
- Autoimmune Hepatitis: Half of affected pts < 20yrs; peak incidence before puberty
- Biliary Atresia: 1:5000-12,000 newborns
- Pediatric liver transplant: 7.8% of all liver transplants in US
Transition to Adult Care

Defined by The Society for Adolescent Medicine as:

“purposeful, planned movement of adolescents and young adults with chronic physical and medical conditions from child-centered to adult-oriented health-care systems”
Transition to adult care

- Reasons youth may be discharged from pediatric care

- Displaying “adult behaviors”:
  - Sexual activity
  - Pregnancy
  - Illegal substance abuse
  - Adjudication to juvenile justice system
  - Insubordination to authority
Transition Process

**Birth**

**Childhood**

**Adolescence**
By 12-13 yrs of age, young people are gradually helped to develop knowledge and self management skills.

**Transfer**
Ideally between 18-21yrs of age.

**Emerging Adulthood**
At 18-25yrs of age, knowledge & self management will continue to develop. Focus is on responsibility and decision making.
Transition to Adult Care

American Academy of Pediatrics (AAP) in conjunction with the American Academy of Family Physicians & American College of Physicians”

Best practice guidelines:
- Transition planning should start at 12yrs
- Transfer from child to adult oriented care between 18-21yrs
- Should be part of standard clinical care for all youth/young adults
- Every patient should have individualized transition plan

Differences in care model

- Pediatric care
  - Family focused
  - Close parental involvement
  - Multi-disciplinary team (RD, SW, Psychologist/Psychiatrist)
  - Treatment focus on growth, nutritional optimization and minimizing ionizing radiation
  - Stress of disease on physical, developmental and psychosocial milestones

- Adult care
  - Patient treated as independent consumer of health services
  - Treatment focus geared toward symptom control, endoscopic remission and management of disability
  - Comorbid illness and concurrent polypharmacy
  - Cancer surveillance and prevention
  - Impact of tobacco use, drug use and sexual activity
Why is it important?

- Patients get lost to follow-up during transition of care
- Medication adherence may drop
- Disease complications (i.e., IBD flares, chronic rejection or graft loss, food impactions etc)
- More ED visits
- Increased hospitalizations
- Increased healthcare costs
Survey Data

- National survey (363 adult GI MDs)
  - MDs identified knowledge about medications, medical history and impact on lifestyle behaviors (ie. drugs, smoking) as essential patient competencies for successful transfer of care
  - 55% reported that young adults with IBD demonstrated deficits in knowledge of their medical history
  - 69% reported patients knew little about their medication regimens

Adolescents with IBD

- Canadian study (Bechimol 2011)
  - Only 55% of adolescents with IBD could recall when they were diagnosed
  - < 25% recalled disease location

- Another study (Fishman 2010)
  - Only 43% adolescents with IBD knew their medications and had poor knowledge about medication SE’s
Pediatric liver transplant recipients (Annunziato 2008)
- Less than half patients bt 18-25yrs made own appts or understood insurance issues

Celiac disease (O’Leary et al 2004)
- Patients w discontinuous follow-up after pediatric stage frequently (50%) abandon GFD
- Ongoing medical support and follow-up shown to improve disease outcome and pt’s compliance to GFD
Structured transition process

- Liver transplant
  - Patients who had access to transition coordinator had better medication adherence 1 yr after transfer compared with pts who did not.
  - Significant reduction in variation of serum immunosuppressant levels in association w reduction in elevated liver enzymes (Annunziato 2008)

- Type 1 Diabetes
  - Improvement in glycemic control – reduced HbA1c (Cadario 2009)
  - Reduction in number and duration of admissions for DKA (Holmes-Walker 2007)

- Juvenile Arthritis
  - Improvement in Quality of Life (QOL) in both patients and their parents (McDonagh 2007)
Adolescents and Emerging adults

- Adolescence marked by period of pubertal, emotional and cognitive development

- Emerging adults (bt 18-25yrs)
  - “in-between” age
  - Marked by instability in employment, higher education, residential status, financial independence
  - Gaps in insurance coverage
Barriers

- Patient/parent resistance to transfer
  - Fear, anxiety about change
- Pediatric caregiver reluctance to relinquish care “lose the patient”
- Immaturity
- Lack of independence
- Poor knowledge
- Nonadherence
Important Aspects of Transition

- Individualized planning
- Development of self-management skills
- Assessment of transition readiness
- Identification of adult provider
- Communication of key information from pediatric to adult provider
Assessment of Transition Readiness

- Assessment of transition readiness
  - Provides estimate of patient skills (more accurate than provider opinions)
  - Allows providers to identify gaps in patient skills
  - Track skill acquisition over time
  - Set individually tailored goals for transition
Predictors of success

- Pt's developmental maturity is one of the greatest predictors of transition success
- Difficulty with abstract reasoning → predictive of failed transition
  - Understanding that absence of symptoms may not correlate to disease activity
  - Emphasizing need to take meds despite feeling "well"
Assessing Transition Readiness

- Self Advocacy
- Self Management
- Knowledge
- Other (day-to-day tasks)
**Transition Readiness**

**Self Management**
- Take medications correctly
- Take care of medical equipment/supplies
- Fill own prescriptions
- Make own appointments
- Obtain referrals for labs/clinic visits

**Self Advocacy**
- Contact MD/RN when problems arise
- Ask questions at clinic visit
- Request accommodations at school/work
- Use community support services
- Maintain health records
Transition Readiness

Knowledge
- Diagnosis
- Basic medical history
- Rationale for treatment
- Names and doses of medications
- Potential complications of disease and treatments

Other
- Prepare own meals
- Healthy choices re: diet & lifestyle
- Avoid risky behaviors
  - Unsafe sexual activity
  - Drugs and tobacco
  - Bad hygiene
Timing

- Timing should be individualized and flexible
- Pts should be in quiescent or mild disease state at time of transfer
- Need to take into account pt’s physical, psychological, cognitive and social maturity
- Milestones serve as natural junctures (graduating school, moving out of the house etc)
- Helpful to discuss with family and patient, to determine mutually agreed upon target age (ideally 1-3 years before)
Timing: When to wait

- Impending changes in treatment plan
- Surgery
- Disease flare
- Times of major social upheaval
Models of Transition

- Joint adult & pediatric clinics
- Unique transition clinic
- Alternating visits
- Coordinator initiated transition
- Preparation with patients using assessment tools
Team Effort

- Shared responsibility across disciplines is important
  - GI specialist, PMD, nurses, nurse practitioners, social worker etc.

- Multidisciplinary process
  - MD/APN/RN – medical aspects of transition (knowledge, medical history:
  - Psychologists/SW – nonadherence, family dynamics, behavioral/emotional factors (anxiety, depression)
  - Social Workers – resources to help facilitate transition (health insurance, training in self advocacy)
Tools for Transition

- TRAQ
- Transition Readiness Assessment Questionnaire
- My Health Passport

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<th>Name</th>
<th>MyHealth Passport Example</th>
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<tr>
<td>Diagnosis</td>
<td>Crohn disease (2010)</td>
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<td>Location</td>
<td>Esoph., terminal ileum, R colitis</td>
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<tr>
<td>Perianal</td>
<td>Skin tags, Fistulace</td>
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<tr>
<td>xtra intes</td>
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<td>Family Hx</td>
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<td>Asthma</td>
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<td># adm date last</td>
<td>2x, January 2010</td>
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<td>Meds</td>
<td>MTX</td>
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<tr>
<td>Vitamins</td>
<td>Multivit, Calcium, Vit D</td>
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<td>WARNING</td>
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<td>Drug allergies</td>
<td>Penicillin</td>
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<td>Immunization</td>
<td>Routine immunizations up to date</td>
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<td>Chickenpox</td>
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<tr>
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<tr>
<td>Paediatrician</td>
<td>Dr. Smith - (000)555-1111</td>
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<tr>
<td>Family Doctor</td>
<td>Dr. Jones - (000)555-1112</td>
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<tr>
<td>GI ped</td>
<td>Dr. Singh - (000)555-1113</td>
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<tr>
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<tr>
<td>ICE</td>
<td>Mom - (000)555-1115</td>
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<td>Date Created</td>
<td>5/10/2010 <a href="http://www.sickkids.ca/MyHealthPassport">www.sickkids.ca/MyHealthPassport</a></td>
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Pediatric gastroenterologist

- Start discussions early
- Ask patients and family members their expectations of the transition process
- Use assessment tools to assess patient readiness
- Allow patients to spend some of the visit alone without parents
- Highlight differences between pediatric & adult care
- Prepare health summary at time of transfer of care
Adult Gastroenterologist

- Anticipate parental involvement at initial clinic visits
- Be sensitive to family centered care the patient will be leaving
- Anticipate questions about impact of treatment on body image and sexual health
- Educate patient in understanding the adult health care system
- Expect newly transferred patients to require longer appointment times for first few visits
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Summary

- Transition of care from pediatric to adult GI care is a gradual process

- Smooth, timely transfer is crucial for high-quality health care

- Successful transfer of care
  - Saves time and resources
  - Prevents complications and unnecessary hospitalizations

- Transition readiness tools can help during this process
Thank you