Medical Transition of Youth with Special Health Care Needs

Tisa M Johnson-Hooper MD

Objectives:

Identify effective methods for the practical application of concepts related to improving the delivery of services for persons with developmental disabilities

Notes:
Healthcare Transition for Youth with Special Health Care Needs
Tisa M. Johnson-Hooper MD

Objectives

- Understand the term Health Care Transition
- Appreciate the fundamental steps in effective health care transition for youth, including those with special health care needs
- Review transition tools available to assist with the implementation of a transition process in a primary care practice
- Examine a current healthcare quality improvement initiative

Morning patients

- Camille is a 17 year old girl with a long standing history of severe, persistent asthma, who presents with a 3 day history of increased work of breathing and wheezing.
- Matthew is a 14 year old boy who presents for his first well child visit. Matthew has a diagnosis of ASD. His parents are concerned with a recent staring episodes.
- Anne is a 13 year old girl with generalized lipodystrophy, DM, dermatomyositis, and hypertriglyceridemia who presents for hospitalization follow up for acute pancreatitis.
- Kayla is a 18 year old who comes in for a nurse only appointment to receive her final HPV vaccine. She graduates in 6 weeks. Needs paperwork for a summer travel.

Healthcare Transition

- During which of these visits should medical transition planning occur?
- Which patient would be easiest to transfer care to adult medicine?
- What is the patient’s role in the transition process?
- What are the specific tasks of the pediatric care provider? Adult provider?
- What is the typical way patients get to adult medicine?

What is Health Care Transition (HCT)?

Need for Transition Improvements

- All Adolescents need to transition to adult-centered care
  - There are an estimated 60 million adolescents/young adults, ages 12-25
  - 18 million adolescents are ages 18-21, about 1/3 of whom have chronic conditions
- Without transition support, data show health is diminished, quality of care is compromised, and health care costs are increased*
- Majority of youth and families are ill-prepared for this change.
- Surveys of health care providers consistently show they lack a systematic way to support youth, families, and young adults in transition from pediatric to adult health care
- Patients age 18-26 have the 2nd highest ED utilization rate (after >75 year olds) any data on special needs subgroup???

**Supporting the Health Care Transition From Adolescence to Adulthood in the Medical Home**

AAP, AAFP, ACP, Transitions Clinical Report Authoring Group

Pediatrics 2011; 128:182

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**Medical Home**

A Medical Home is an *approach* to providing high quality and cost effective health care rather than a structure or health care complex.

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**Background: AAP/AAFP/ACP Clinical Report on Health Care Transition**

- **In 2011**, Clinical Report on Transition published as joint policy by AAP/AAFP/ACP
- **Targets all youth**, beginning at age 12
- **Algorithmic structure with:**
  - Branching for youth with special health care needs
  - Application to primary and specialty practices
  - Extends through transfer of care to adult medical home and adult specialists

- **Age 12**: Youth and family aware of transition policy
- **Age 14**: Health care transition planning initiated
- **Age 16**: Preparation of youth and parents for adult approach to care and discussion of preferences and timing for transfer to adult health care
- **Age 18**: Transition to adult approach to care
- **Age 18-22**: Transfer of care to adult medical home and specialists with transfer package

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**Failed Transition to Adult Medicine**

- **Refusers** – patients/families who would not consider a transition
- **Vacationers** – patients/families who would leave but quickly returned
- **Interviewers** – patients/families who continually changed physicians after brief encounters
**Medical Home Common Elements**

- Family Centered
- Continuous.
- Comprehensive
- Accessible
- Coordinated
- Compassionate
- Culturally Competent

**Children with Special Health Care Needs (CYSHCN)**

Those children who have or at risk for chronic physical, developmental, behavioral, or emotional conditions who require health related services of a type or amount beyond that required by children generally.

*The Federal Maternal and Child Health Bureau, 1997*

**Six Core Elements of Health Care Transition: QI Model**

- Original Six Core Elements (1.0), developed in 2011, as QI strategy based on AAP/AAFP/ACP Clinical Report with set of sample tools and transition index.
- HCT Learning Collaboratives (with primary and specialty care practices)
  - Conducted between 2010-2012 in DC, Boston, Denver, New Hampshire, Minnesota, Wisconsin
  - Used well-tested Learning Collaborative methodology from the National Initiative for Children’s Healthcare Quality and pioneered by Institute for Healthcare Improvement
  - Demonstrated Six Core Elements and tools feasible to use in clinical settings and resulted in quality improvements in transition process*


**Six Core Elements of Health Care Transition**

1. Transition Policy
2. Transition Tracking and Monitoring
3. Transition Readiness
4. Transition Planning
5. Transfer of Care
6. Transfer Completion

**Six Core Elements 2.0***

- Transitioning Youth to Adult Health Care Providers (Pediatric, Family Medicine, and Med-Peds Providers)
- Transitioning to an Adult Approach to Care Without Changing Providers (Family Medicine and Med-Peds Providers)
- Integrating Young Adults into Adult Health Care (Internal Medicine, Family Medicine, and Med-Peds Providers)

*See www.gottransition.org for customizable packages in English and Spanish.

**Sample Forms and Templates**

- Discuss transition policy
- Track progress
- Assess self-care skills
- Develop transition plan
- Prepare transfer documents
- Confirm transfer completion
Measurement Approaches

- Measurement approaches available and tailored to each of the three packages
- Options:
  - Sample HCT Feedback Survey for Youth/young adults/parents/Caregivers (available at gottransition.org)
  - Current assessment of Health Care Transition Activities (qualitative self-assessment method to determine the level of HCT support available to youth/families—see handout/available at gottransition.org)
  - Health Care Transition Process Measurement Tool (objective scoring method to assess progress in implementing the 6 CE and dissemination to all youth ages 12 and older—see handout/available at gottransition.org)

Goals & Objectives

- Develop a HCT process that can be disseminated throughout the HFHS
- Positively impact adolescent knowledge base and healthcare skills
- Improve primary care healthcare utilization of patients 17-22 years old
- Improve patient and provider satisfaction

HFHS HCT QI Initiative

- Leadership engagement - Spring 2014
  - HCT provided HFHS a mechanism to support the shift in physician RVU targets to panel size targets
  - Enhance value
  - HCT QI Team - 10/2014
    - 4 practice sites (2 pediatric & 2 IM)
    - Physicians, nurse supervisors, pediatrics administrator, patient partner, administrative fellow
    - Meet by phone monthly
    - Current Assessment of HCT Activities

HFHS HCT QI Initiative

- Healthcare Transition Webinar - 10/2014 (GT)
- Henry Ford Internal Medicine Approach to Healthcare Transition
- AVS Content - 12/2014-3/2015
  - Tips for Healthcare Transition for Youth with Developmental or Intellectual Disabilities
  - Tips for Healthcare Transition for Young Teens: After Your Teen’s Visit
  - Tips for Healthcare Transition for Middle and Late Teens: After Your Visit
  - Tips for Young Adults Transitioning From Pediatric Care Providers

MyChart Healthcare Skills Questionnaire pilot - 7/2015-present

When patients aged 16-20 are scheduled for a CHILD EXTENDED VISIT/PHYSICAL in certain departments, the TRANSITION READINESS ASSESSMENT – YOUTH questionnaire will automatically be attached to the scheduled appointment.

When patients log into their MyChart, they will see a message to “Please fill out your questionnaires before coming” on the Upcoming Appointment alert on their homepage.

Clicking on the alert takes them to the Appointment Details screen.
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The responses will also be available to the provider within the scheduled encounter via the Questionnaires section.

There is a scoring question at the bottom of the questionnaire that adds up the patient’s responses and gives:

- 2 points for every “Yes, I know this,”
- 1 point for every “I need to learn,”
- 0 points for every “Someone needs to do this?”

**HFHS HCT QI Initiative**

- Epic care plan - 8/2015-present
- Youth with special health care needs will require a plan that also incorporates:
  - Baseline neurological/functional status
  - Cognitive status (including formal test results)
  - Condition specific emergency plans & contacts
  - Advanced directive
  - Communication preference
  - Identification of proxy or guardian
  - Education/vocation
  - Insurance (SSI)
  - Community resources
HFHS HCT QI Initiative

- Adult Medicine Primary Care Epic referral process - 8/2015 - 1/2016
- Meet and Greet Pilot – (planning stages since 12/2016)
  - Develop a process of referral from Pediatrics to Adult medicine
  - Develop a standard for the initial adult medicine visit

Adult provider survey

1. Are you interested in accepting new young adult patients with or without common chronic conditions (asthma)?
2. Are you interested in accepting new young adult patients with the following:
   - Mental health conditions
   - Intellectual or developmental disabilities
   - Pediatric onset diseases
3. If you prefer to limit or not accept new young patients, what are the important reasons for this decision:
4. Important reasons for limiting or not accept new young patients:

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Questions?