Practical Tips for Healthcare Transition

Jordan Kemere, MD MS FACP

Transition Medicine Clinic

Baylor College of Medicine

GIVING LIFE TO POSSIBLE

Texas Children's Hospital®

Healthcare Transition

- The planned process for adolescents and young adults to transition from pediatric to adult healthcare providers, facilities, and framework.

Objectives

- Identify common barriers to a successful transition
- Recognize opportunities to talk transition early and often
- Learn what is helpful for adult primary care providers

Transition Medicine Clinic

- I have no financial disclosures
- Patient-centered medical home for adults (>18yo) with Intellectual and/or Developmental Disabilities (IDD)
  - primary care
  - social work services
  - case management
  - Assist with transition to adult subspecialists as needed and to adult life
  - Provide interprofessional education to a multitude of healthcare learners
- 1200 patients (Down syndrome, spina bifida, cerebral palsy, autism, other genetic syndromes)

Every
make

At the end of our time today, you will pick one practice change going forward that will improve healthcare transition and thus improve patient care!

Pediatric geneticist → adult geneticist + adult PCP

Pediatric geneticist (sees briefly) → pediatrician

Adult geneticist → adult PCP

Data on Transition – Assessment phase

Table 4 Support referrals and transition preparedness of children (n = 543) and adults (n = 1133) with genetic conditions, National Genetics Education and Consumer Network Survey, 2013

Transition [a]	
Visit doctors or other health care providers that treat only children	88.6
Doctor had talked about eventually seeing doctors or other health care providers who treat adults	9.7
Doctor had talked about health care needs as individual becomes an adult	18.1

[a]Restricted to respondents 11–17 years of age

Transition [a]		
Visit doctors or other health care providers that treat only children	88.6	n/a
Doctor had talked about eventually seeing doctors or other health care providers who treat adults	9.7	n/a
Doctor had talked about health care needs as individual becomes an adult	18.1	n/a

[a]Restricted to respondents 11–17 years of age

Sharon Romelczyk et al and NCC education workgroup, Matern Child Health J (2015) 19:2215-2222

Barriers to a successful transition

- Time!
- Lack of social work and case management support
- Unclear roles – primary care vs subspecialists (including geneticists)
- Lack of adult provider knowledge / adult provider fear
- Changes in insurance and additional supports/funding

Got Transition – Six Core Elements

1. **POLICY/GUIDE**
   Develop, discuss, and share transition and care policy/guide
   AGE 12-14
2. **TRACKING & MONITORING**
   Track progress using a flow sheet registry
   AGE 14-18
3. **READINESS**
   Assess self-care skills and offer education on identified needs
   AGE 14-18
4. **PLANNING**
   Develop HCT plan with medical summary
   AGE 14-18
5. **TRANSFER OF CARE**
   Transfer to adult-centered care and to an adult practice
   AGE 18-21
6. **TRANSITION COMPLETION**
   Confirm transfer completion and elicit consumer feedback
   AGE 18-23

Phase 1 – early adolescence (ages 12-16)

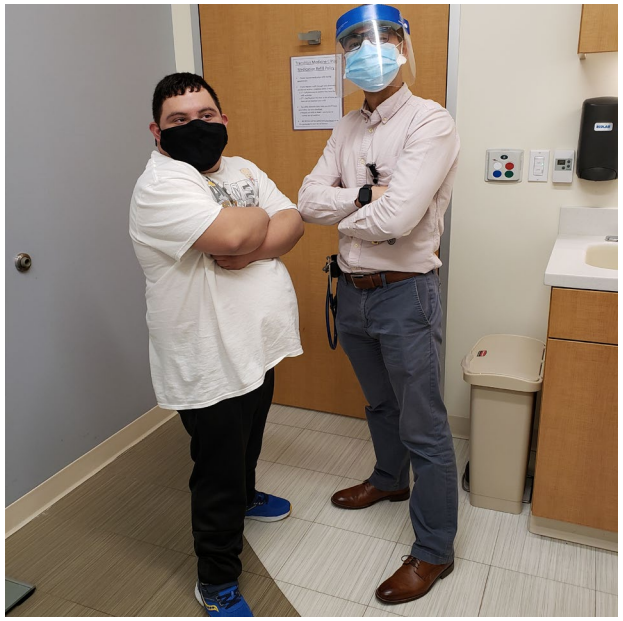
- **Increase Knowledge**
  - Create a **written transition policy** and distribute it to patients well in advance of transition
  - Revisit the **basics of the genetic condition** and **inheritance pattern** with parents and with patients themselves -perhaps for the first time!
- **Explore self-management skills**
  - Practice practice practice
  - **Meet with the adolescent by themselves**

Phase 1 – early adolescence (ages 12-16) Patients and parents

Changing from adult to pediatric healthcare is more than just making a doctor's appointment….

- **Birth to 17 – planning!**
  - **Waivers**
  - **Self management skills**
  - **Getting organized – medical summary, healthcare team**

Phase 2 – late adolescence (ages 14-18)



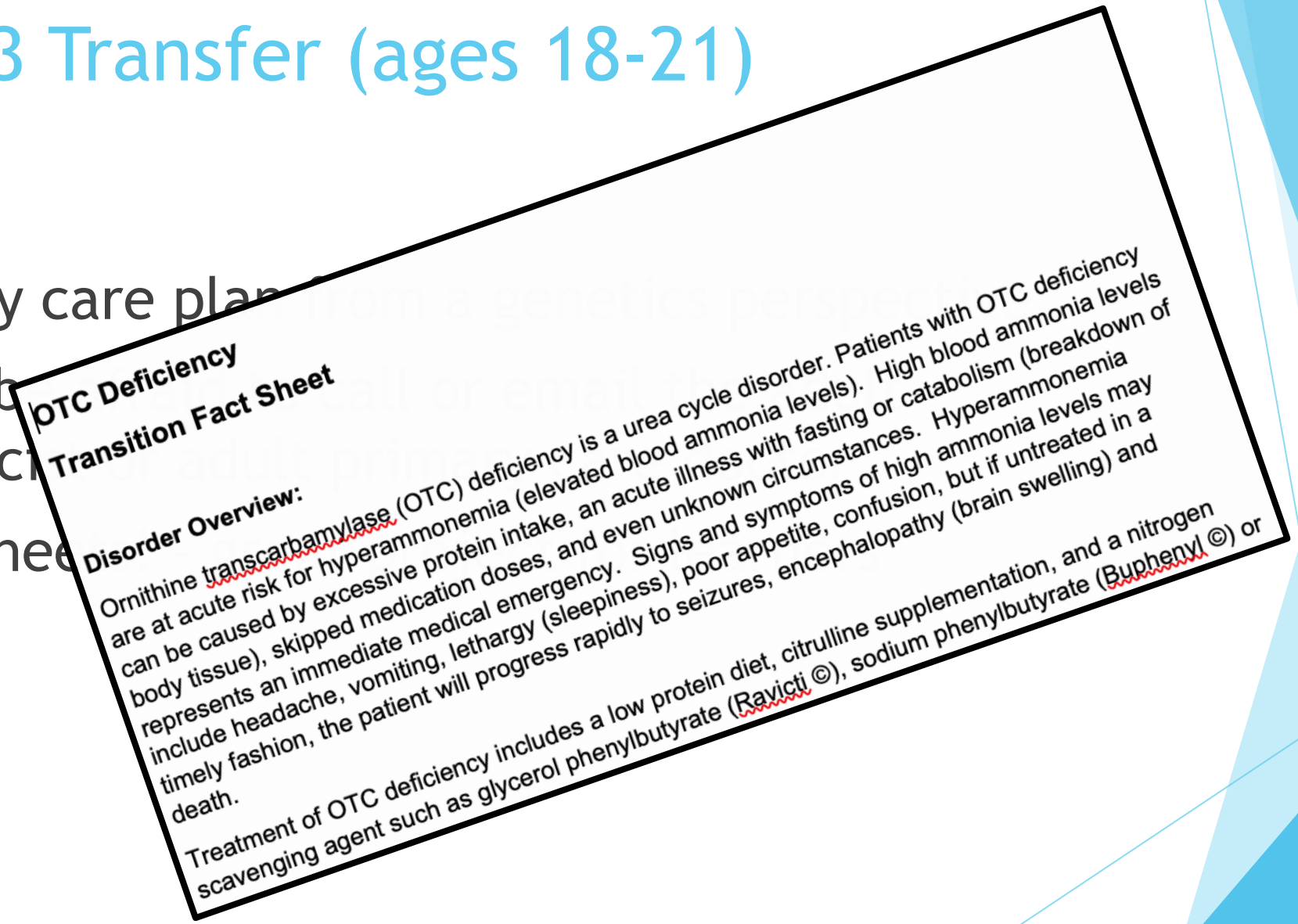
- Self—management and Safety
  - How do you make a doctor's appointment?
  - Who do you call in an emergency?
  - Emergency letters and safety bracelets
- Identify adult partners – genetics and primary care
- If you have social work support in your clinic, use it!!
  - insurance, adult disability determination, decision-making supports, education/job planning

Phase 2 – late adolescence (ages 17-19) Patients and Parents

- **Details!**
  - **Social security determination**
  - **Consent and guardianship**
  - **Transfer to adult providers?**

Phase 3 Transfer (ages 18-21)

- Solidify care plan from a genetics perspective
- Don't b… call or email if… genetici… adult prim…
- Fact Shee…



OTC Deficiency

Transition Fact Sheet

Disorder Overview:

Ornithine transcarbamylase (OTC) deficiency is a urea cycle disorder. Patients with OTC deficiency are at acute risk for hyperammonemia (elevated blood ammonia levels). High blood ammonia levels can be caused by excessive protein intake, an acute illness with fasting or catabolism (breakdown of body tissue), skipped medication doses, and even unknown circumstances. Hyperammonemia represents an immediate medical emergency. Signs and symptoms of high ammonia levels may include headache, vomiting, lethargy (sleepiness), poor appetite, confusion, but if untreated in a timely fashion, the patient will progress rapidly to seizures, encephalopathy (brain swelling) and death.

Treatment of OTC deficiency includes a low protein diet, citrulline supplementation, and a nitrogen scavenging agent such as glycerol phenylbutyrate (Ravicti ©), sodium phenylbutyrate (Buphenyl ©) or

Phase 3 Transfer (Ages 20-22) Patients and Parents

- **Transfer of many things -- not just doctors!**
  - **Insurance, insurance, insurance!**
  - **Nursing hours**
  - **Education and Employment**
  - **Dental care**

Part 4 Post Transfer (ages >21)

- Call or email your pediatric/adult counterpart to give feedback and ask questions
- How often will you see the adult patient with a known and stably managed genetic condition? Communicate this with the patient and other providers

Part 4 Post Transfer (age >22) Patients and Parents

- Ages 22 and beyond
  - Insurance (again! At age 26 and medicare)
  - Long term planning
  - Stay Informed

Tips

- Transition is a process and you can never start too early
- Utilize your whole team/staff
  - What can students, residents, medical assistants, nurses, case managers, social workers do??
- Set small, achievable goals – pick something and work on
  - Makes a great QI project
- Make friends with primary care doctors and your pediatric/adult genetic counterparts

Questions?

- Feel free to email me with any questions about transition or medical education!

Jordan Kemere

kemere@bcm.edu

Thank you to all my colleagues at the Transition Medicine Clinic and at TCH -- Especially Dr. Lindsay Burrage!

Additional References and Resources

- The Arc – thearc.org
- National Disability Rights Network - https://www.ndrn.org/
- Got Transition - https://www.gottransition.org/
- Fremion E, Cowley R, Berens J, Staggers KA, Kemere KJ, Kim JL, Acosta E, Peacock C. Improved health care transition for young adults with developmental disabilities referred from designated transition clinics. J Pediatr Nurs. 2022 Jul 23;67:27-33. doi: 10.1016/j.pedn.2022.07.015. Epub ahead of print. PMID: 35882113.