



The Role of Primary Care in the Transition from Pediatric to Adult-Oriented Care

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Outline

- Background
- The Transition Controversy
- The Case for Transfer
- Tips and Tricks

The Good News

- Modern medicine has changed the natural history of diseases previously fatal in childhood.

Examples

- Median survival in Cystic Fibrosis
 - Less than age 20 in 1985
 - 37 years old as of 2006
- 5-year survival rates for pediatric ALL
 - < 10% in the 1960's
 - 90% in 2005

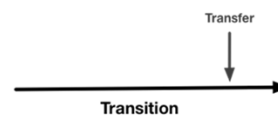
Transition Guidelines

- Developed jointly by the AAP, ACP, and AAFP
- Most recent update published in 2018
- Mostly the product of expert opinion



Transition vs. Transfer

- Transition: Process of change that includes:
 - Development of self-management skills
 - Increase in independence
 - Move from pediatric to adult-oriented care (transfer)
 - Establishment in an adult-oriented care setting



Implications for Doctors for Adults

- Adult-oriented providers, especially primary care providers, have clear roles in the transition process.
 - Participating in transfer
 - Assisting patients as they get established in adult-oriented care

Continued Controversy

- Regardless of age, those with childhood-onset conditions should only be seen by the experts on those conditions

Continued Controversy

- Regardless of age, those with childhood-onset conditions should only be seen by the experts on those conditions
- That is unnecessary overkill for most young adults. Transfer should be the goal.

The Arguments for Staying

- Increase in morbidity / mortality after transfer
- Poor patient and family experience after transfer
- General discomfort among adult-oriented providers
- Difficulties of communication

Increase in Morbidity / Mortality

- Increase in mortality after transfer for young adults with sickle cell disease
- Increase in diabetes-related hospitalizations after transfer for young adults with diabetes
- High rates of graft loss after transfer in transplant patients.

Limitations

- Observational
- Patients accumulate morbidity with time
- Teens / young adults are at high risk in general

Poor Patient/Family Experience

- Young adults report that adult doctors don't listen to them
- Parents report that adult doctors don't listen to them
- Many get frustrated when they feel like they know more about the disease than the doctor does

Uncomfortable Adult-Oriented Providers

- Practicing internists ranked lack of training in pediatric conditions as the largest barrier to transition
- Internal medicine residents report being less confident than pediatric residents in the care of young adults with pediatric-onset illness

Difficulties of Communication

- Providers report that it is difficult to discuss a patient about to transfer:
 - 40 % of general internists
 - 45% of general pediatricians
- Adult specialists also feel that they don't get enough information from the pediatric providers

The Arguments for Transferring

- The Math Doesn't Work
- Transfer = Opportunity to Improve Care
 - Case Example

The Math Doesn't Work

- Numbers of "transition patients":
 - 400,000 adult survivors of pediatric cancers
 - 1 million adults with type 1 diabetes
 - 1.2 million adults with an intellectual disability
 - 800,000 adults with congenital heart disease
- Numbers will continue to grow
 - 1 in 68 20-year-olds has autism
 - NICU survival rates continue to improve

A Case

- John is a 22 year old male with Down syndrome.
- PMHx:
 - Asthma – severe exacerbation requiring PICU stay at age 10; well-controlled on inhaled fluticasone
 - Hypothyroidism – diagnosed on screening at age 12; on levothyroxine; last TSH was 1.9
 - Anxiety – on citalopram and going to group therapy, which is working well

Case (cont.)

- John would like to get a part-time job.
- His mother worries that he won't be able to get time off to get to "all the doctor's visits and appointments he has to have."



“How many doctors’ visits does he go to?”

Well, let's see...

- Every 3 months to the pediatric pulmonologist
- Every 6 months to the pediatric endocrinologist
- Every 6 months to the pediatric psychiatrist
- Every 6 months to check in with the PCP
- 3-5 times a year for acute visits
- Monthly group therapy sessions for anxiety

27 total visits in a year!!

Opportunity to Simplify Care

- In John's case...
 - Asthma is controlled → no adult pulmonologist
 - Hypothyroidism is treated → No adult endocrinologist
 - Anxiety → straight-forward treatment plan in place
 - Therapy should probably continue
 - No adult psychiatrist

How this happens...

- Specialists are easy to add, but hard to subtract.
 - Specialists and PCPs sometimes disagree about who is appropriate to transfer back to primary care
 - Even when doctors agree that transfer back to primary care is appropriate, fear that patients will not be amenable to transfer.

Pediatrics is different...

- Standard of care in pediatrics is to refer things that may not necessitate referral for an adult
 - Type II Diabetes → Refer to endocrine
 - Hypothyroidism → Refer to endocrine
 - Hypertension → Refer to nephrology or cardiology

Going back to the case

- Specialists were probably all appropriate when John was younger
- Transfer represents an opportunity to re-evaluate and simplify care

But...**But...**

- I still don't know what half these diseases are.
- I don't know how to do a visit with a young adult patient and their parent(s).
- There's all the non-medical stuff to think about.

GeneReviews

- Your key to succinct information on genetic disorders
- Online book on PubMed that organizes NIH resources on genetic disorders to make them more easily searchable
- Freely available to anyone
- Ex. Tuberous sclerosis

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To ensure continuing relevant and medically actionable content, each GeneReviews chapter is updated every four to five years (or as needed) by the author(s) in a formal and comprehensive process created by the GeneReviews editors. Additional updates may occur more frequently as needed to reflect significant changes in clinically relevant information.

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- 3. Sattler EC, Steinlein OK. 2006 Feb 27 [Updated 2024 Dec 5].
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- [Legius Syndrome](#)
- 4. Legius E, Stevenson D. 2010 Oct 14 [Updated 2020 Aug 6].
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Summary Go to:

Clinical characteristics. Tuberous sclerosis complex (TSC) involves abnormalities of the skin (hypomelanotic macules, facial angiofibromas, shagreen patches, cephalic plaques, ungual fibromas); brain (cortical dysplasia, subependymal nodules and subependymal giant cell astrocytomas [SEGAs]), seizures, intellectual disability/developmental delay, psychiatric illness); kidney (angiomyolipomas, cysts, renal cell carcinomas); heart (rhabdomyomas, arrhythmias); and lungs (lymphangiomyomatosis [LAM]). CNS tumors are the leading cause of morbidity and mortality; renal disease is the second leading cause of early death.

Diagnosis/testing. The diagnosis of TSC is based on clinical findings. Heterozygous pathogenic variants can be identified in 75%-90% of individuals who meet the clinical diagnostic criteria for TSC. Among those in whom a pathogenic variant can be identified, pathogenic variants in *TSC1* are found in 31% and pathogenic variants in *TSC2* in 69%.

Management. Treatment of manifestations: For enlarging SEGAs: mTOR inhibitors; neurosurgery when size causes life-threatening neurologic symptoms. For seizures: vigabatrin and other antiepileptic drugs, and on occasion, epilepsy surgery. For renal angiomyolipomas >4 cm, or >3 cm and growing rapidly: mTOR inhibitors are the recommended first line of therapy with secondary therapy options being embolization or renal sparing surgery. For LAM: mTOR inhibitors. For facial angiofibromas: topical mTOR inhibitors. For symptomatic cardiac rhabdomyomas: surgical intervention or consideration of mTOR inhibitor therapy.

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Tips for Working with Parents

- When young adult patients are neurotypical
- When young adult patients have a developmental disability

When Patients are Neurotypical

- Don't:
 - Kick parents out right away.
 - Ignore parents entirely.

When Patients are Neurotypical

- Don't:
 - Kick parents out right away.
 - Ignore parents entirely.
- Do:
 - Give the patient some one-on-one time.
 - Give the patient priority
 - Primarily look at and talk to patient
 - Confirm any information offered by parents with the patient

When Patients have a Disability

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- Try to do a little homework on the patient and his or her main diagnosis.

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- Be honest about what you do and don't know, but don't be defeatist.

When Patients have a Disability

- Try to do a little homework on the patient and his or her main diagnosis.
- Be honest about what you do and don't know, but don't be defeatist.
- LISTEN to parents.

The “Non-Medical” Stuff

- Examples:
 - Job / Volunteering / Education Opportunities
 - Guardianship / Surrogate Decision-Making
- You do NOT have to be the expert on these things.
- You DO want to familiarize yourselves with the resources around you.

Job Supports

- Office of Vocational Rehabilitation
 - Every state has at least one
 - Names vary
 - Ohio = Opportunities for Ohioans with Disabilities
 - Goal: Helping people achieve maximum function
 - Lots of tools in their tool box

Educational Opportunities

- Many universities have established Comprehensive Transition and Post-Secondary (CTP) Programs
- Example: University of Cincinnati Transition and Access Pathway (TAP)
- To find, try searching for "life skills program"

Guardianship / Surrogate Decision-making

- May or may not have been addressed prior to transfer
- Can become a problem if not pinned down
- Alternatives to full-on guardianship exist

Guardianship Resources

- Disability Rights Ohio website
- The ARC website in your state

Conclusions

- Transition is a process that continues to have its controversies.
- Nonetheless, primary care has an important role to play in transition.
- Resources to help are out there.