Transitioning from Pediatric to Adult Care: Improving Clinical Care for Adolescents with Chronic Disease

Keila N. Lopez MD, MPH
Nicole Broussard, LCSW
DK Lovick BSN, RN, CCCTM
Transitioning from Pediatric to Adult Care: Improving Clinical Care for Adolescents with Chronic Disease

Web: PollEv.com/drklopez
Text: DRKLOPEZ to 37607 once to join
OUTLINE

• Increasing numbers of youth with chronic disease
• Transition vs. transfer
• Transition: stakeholders and establishing standard of care
• The adolescent brain
• Concerns/deficiencies in adolescents with chronic disease
• Cardiology strategies to connect and improve transition
  - Teens
  - Providers
• Everyone can help transition adolescents with chronic dz
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Between 1960 and 2005 the percentage of children with a chronic disease in the US almost quadrupled.

13–27% of children are affected by chronic conditions.

Racial/ethnic minorities are 1.5 to 2.0 times more likely than whites to have major chronic diseases.

Chronic disease is more common in those with lower SES.
• Hardelid classification
- Any health problem requiring clinical follow-up for >12 months in 50% or more of cases. Medical follow-up was defined as repeated hospital admission, specialist follow-up through outpatient department visits or use of support services (PT/OT).
- Data sources: Hospital administrative data for England and death registrations.

• Feudtner classification
- Any medical condition that can reasonably be expected to last at least 12 months (or until death) and involve either several different organ systems or one organ system severely requiring specialty pediatric care with likely hospitalization in a tertiary care center.
- Data sources: Death records, hospital admissions and emergency department data.

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For Young adults with chronic disease, what is the difference between Transition and Transfer of Care?

Transition of care is specific to only parents, Transfer of Care is specific to only adolescents.

Transition and Transfer of care have essentially the same meaning.

Transition of care refers to transitioning responsibilities from parent to patient. Transfer of care refers to switching from pediatric to adult care providers.

Transition of care refers to transitioning responsibilities from pediatric to adult provider. Transfer of care refers to transferring responsibilities from parent to adolescent.
GOAL OF TRANSITION

• Transition of care: A shift in the responsibility of health care management from the parents to the patient

• Transition is a multifaceted process with five perspectives: the patient, the parents, the pediatrician, pediatric cardiologist, and the adult/ACHD cardiologist

• Optimal transition process: uninterrupted, patient-centered, age and developmentally appropriate, flexible, comprehensive, patient education and empowerment
TRANSITION ≠ TRANSFER

• Transition of care: A shift in the responsibility of health care management from the parents to the patient
  • Thoughtful and gradual process
  • Best initiated several years prior to transfer of care

• Transfer of care: movement of patients and their care from one medical facility or provider to another
  • Can be challenging to find ACHD providers
  • Difficult to “leave patient” for pedi cardiologist and parent/patient
Children and Adults With Congenital Heart Disease Lost to Follow-Up: Who and When?

- Patients age 22 years diagnosed before 6 yo with CHD in Quebec, Canada (n=643)
- Three age groups were examined for cardiology follow-up: 6-12 years, 13-17 years, and 18-22 years

Circulation. 2009;120:302-309
POOR TRANSITION IN CHD

-Poor disease knowledge- higher risk
  •Ex- endocarditis

-Lack of needed skills to become an independent adult navigating a complex medical system with a CHD

-Lapses in care= predictor for morbidity
POOR TRANSITION IN CHD

- Inappropriate adult care – may have a complex CHD seeing an adult cardiologist not trained in CHD

- Increased utilization of emergency services = increased healthcare costs

- Worse outcomes for ethnic minorities with CHD, who may suffer from other health disparities
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MAJOR STAKEHOLDERS

Medical Providers

Total number of board certifications awarded

35,000
30,000
25,000
20,000
15,000
10,000
5,000
0

Adult Cardiology
Pediatric Cardiology
ACHD

CHD Patients

Raising a Heart Child
A Parent’s Guide to Congenital Heart Defects

Jennifer Anne Fleming

CHD Parents
### TABLE 2  Barriers perceived by patients, families and healthcare providers to interfere with the transfer of adolescents with CHD from pediatric to adult care

<table>
<thead>
<tr>
<th>Domain</th>
<th>Perceived barriers</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Structural</strong></td>
<td>Insurance availability&lt;br&gt;Subspecialty healthcare training and education&lt;br&gt;Interinstitutional transfer&lt;br&gt;Lack of reimbursement for transition visits and care coordination</td>
</tr>
<tr>
<td><strong>Institutional</strong></td>
<td>Lack of formal transition programs&lt;br&gt;Lack of ACHD provider availability and training&lt;br&gt;Institutional aging-out policies&lt;br&gt;Lack of primary care physicians and hospitalists comfortable caring for CHD&lt;br&gt;Complex navigation</td>
</tr>
<tr>
<td><strong>Social</strong></td>
<td>Provider-patient and provider-parent attachment&lt;br&gt;Patient self-advocacy and knowledge&lt;br&gt;Parental involvement</td>
</tr>
<tr>
<td><strong>Neurocognitive</strong></td>
<td>Developmental delays&lt;br&gt;Disability in social, emotional, executive function domains</td>
</tr>
</tbody>
</table>
ACPC Develops CHD Young Adult Transition and Transfer Policy Quality Metrics

February 9, 2018

ACPC’s Quality Metric Work Group recently developed the CHD Young Adult Transition Policy and the CHD Young Adult Transfer Policy Quality Metrics for use in internal quality improvement programs. These metrics determine whether or not an institution or clinic has official transition/transfer policies in place for young adults with congenital heart disease available in print or online. Click here to view/utilize these metrics. These metrics are designated for use in internal quality improvement programs only and is not appropriate for any other use, e.g., pay for performance, physician ranking or public reporting programs.
CURRENT PRACTICE: POOR TRANSITION TO ADULT CARE
<table>
<thead>
<tr>
<th>Determinants</th>
<th>Association</th>
<th>Loss to follow up/care gap</th>
</tr>
</thead>
<tbody>
<tr>
<td>Sociodemographic</td>
<td>Older age at last pediatric visit(^{17})</td>
<td>Male sex(^{17,48,49})</td>
</tr>
<tr>
<td></td>
<td>Insurance status(^{37})</td>
<td>Last cardiology visit outside a university hospital setting(^{49})</td>
</tr>
<tr>
<td></td>
<td>Presence of a medical home(^{87})</td>
<td>Decreased median family income(^{50})</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Increased distance from clinic(^{88})</td>
</tr>
<tr>
<td>Patient beliefs</td>
<td>Recommendation from pediatric cardiologist for ACHD care(^{17,37})</td>
<td>Lack of awareness of the need for follow-up(^{52})</td>
</tr>
<tr>
<td></td>
<td>Belief that follow-up should be at ACHD center(^{17})</td>
<td>Feeling well(^{53})</td>
</tr>
<tr>
<td></td>
<td>Belief that follow-up should occur annually(^{17})</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Perceived high risk of CHD complications and not attending cardiology</td>
<td></td>
</tr>
<tr>
<td></td>
<td>appointments(^{17})</td>
<td></td>
</tr>
<tr>
<td>Medical history</td>
<td>Increased frequency of pediatric cardiovascular surgeries(^{17})</td>
<td>No prior cardiac surgery(^{48})</td>
</tr>
<tr>
<td></td>
<td>Frequency of adolescent cardiac appointments(^{17})</td>
<td>Fewer visits to a cardiologist(^{49})</td>
</tr>
<tr>
<td>Health status</td>
<td>CHD symptoms(^{17})</td>
<td>Fewer visits to a noncardiologist(^{49})</td>
</tr>
<tr>
<td></td>
<td>Comorbid health conditions(^{17})</td>
<td>One or more missed cardiology appointments(^{50})</td>
</tr>
<tr>
<td></td>
<td>Activity restrictions(^{17})</td>
<td></td>
</tr>
<tr>
<td></td>
<td>No significant alcohol or drug use(^{17})</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Dental antibiotic prophylaxis(^{17})</td>
<td></td>
</tr>
<tr>
<td>Parental involvement</td>
<td>Attending pediatric appointments without parents(^{17})</td>
<td>Living independently from parents(^{52})</td>
</tr>
</tbody>
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“Scientists used to think that human brain development was pretty complete by age 10, that a teenage brain was just an adult brain with fewer miles on it.”

Francis Jensen, neurologist, Boston Children’s Hospital
Judgment last to develop

The area of the brain that controls “executive functions” — including weighing long-term consequences and controlling impulses — is among the last to fully mature. Brain development from childhood to adulthood:

5-year-old brain  Preteen brain  Teen brain  20-year-old brain

*Dorsal lateral prefrontal cortex* (”executive functions”)

Red/yellow: Parts of brain less fully mature

Blue/purple: Parts of brain more fully mature
UNDERSTANDING THE TEENAGE BRAIN

• Highly Developed Limbic System (Stress Response, Sex Drive, Emotional Control)

• Developing Frontal Lobe (Decision Making)
  • This creates a situation where teens allow their stress responses, biological urges, and emotions to guide their behavior.
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COMMON TRANSITION TOPICS

• Knowledge Deficits
• Psychological Concerns
• Healthcare Skills
• Resource Identification
KNOWLEDGE DEFICITS

- Teenage brain/Neurological concerns
- Understanding of Disease
- Emergent vs Urgent Symptoms
- Trajectory of Disease
- Pregnancy and Birth Control
Motivational Interviewing is key!
STAGES OF CHANGE

- MAINTENANCE – maintaining behavior change
- ACTION / WILLPOWER – changing behavior
- PREPARATION / DETERMINATION – getting ready to change
- CONTEMPLATION – acknowledging need for change; but unsure or wanting to
- PRECONTEMPLATION – not yet acknowledging change is needed
- RELAPSE – returning to old behavior; abandoning new changes
LEVEL OF ENGAGEMENT

CURIOSITY – asking questions, critically thinking, proactive, persistence

REFLECTION – answer questions, linking knowledge, discussing

COMPLIANCE – acceptance, minimal effort, lack retention

PASSIVITY – learning and observing but distracted

DEFIANCE – refuse to acknowledge need or receive education
PSYCHOLOGICAL CONCERNS

- Identifying needs
- Anxiety / depression / stress
- Developing independence
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Studies Show...

Depression and anxiety in adults with congenital heart disease: a pilot study.

Bromberg AJ, Braxton PJ, D’Alessio ED, Lantos PN, DelMarco DR.

OBJECTIVE: To examine the presence of depression and anxiety in adults with congenital heart disease and the association of medical severity with depression and anxiety.

DESIGN: Prospective, pilot study.


PATIENTS: Twenty-two adult patients with congenital heart disease followed in an adult cardiology clinic. Patients were selected who had no evidence of emotional or behavioral difficulties (i.e., no symptoms of depression or anxiety). Outcome measures standardized semi-structured psychiatric interview with structured checklist eliciting Diagnostic and Statistical Manual of Mental Disorders, Fourth Edition (DSM-IV) diagnostic criteria for depressive and anxiety disorders, Brief Symptom Inventory (BSI), and the Cardiologist’s Perception of Medical Severity scale.

RESULTS: Among patients who had been assumed to be “well adjusted,” 36.4% were experiencing a diagnosable psychiatric disorder, with anxiety or depressive symptoms being prominent. There were 6 patients (27.3%) who had BSI scores above 63 indicating pathological emotional functioning. There was significant convergent validity between the clinical diagnoses of depression and anxiety using both diagnostic interviews to identify DSM-IV diagnostic conditions and the BSI. There were significant associations between patient’s medical severity scores and with the DSM-IV diagnosis of depression and the BSI global index score and depression subscale.

CONCLUSIONS: This pilot study highlights important concerns about the emotional functioning of many adults facing congenital heart disease, particularly those with complex lesions. From a clinical perspective, this work suggests that health care professionals should be alert for emotional difficulties and the need for psychological intervention for adult survivors of congenital heart disease even among those that are seemingly emotionally well adjusted.

PMID: 12795534 DOI: 10.1684/jcn.2003.28

Introduction: Adolescents with congenital heart disease are at increased risk for developing psychological distress.

Aim of the study: To assess the prevalence of depression and anxiety in adolescents with congenital heart disease, and to identify the predictors related to these disorders.

Methods: This is a cross-sectional case-control study. A total of 60 adolescents with CHD aged from 12-18 years and 30 apparently healthy adolescents were recruited. All participants were assessed using a designed questionnaire, the Children’s Depression Inventory (CDI), the Revised Children Manifest Anxiety Scale (RCMAS), and the Mini International Neuropsychiatric Interview for Children and Adolescents (MINI-Kid).

Results: Prevalence of depression was higher in adolescents with CHD compared to healthy controls (18.3% vs. 3.3%, p = 0.048). Moreover, 30% of adolescents with CHD had anxiety compared to 10% of the control group (p = 0.03). Multivariate analysis of risk factors showed that level of education and symptomatic cardiac functional class were the significant predictors of depression in adolescents with CHD. Likewise, presence of more than one cardiac defect and having more than one cardiac catheterization were significant predictors of anxiety in adolescents with CHD.

Conclusion: Adolescents with CHD are at increased risk of having depression and anxiety, especially those with low level of education, severe cardiac illness and having multiple cardiac catheterizations. Appropriate psychiatric assessment and early intervention can improve the quality of life of adolescents with CHD.
WHY ANXIETY AND DEPRESSION

- Frequent and Lengthy Hospitalizations
- Painful Procedures
- Traumatic Surgeries in Childhood
- Lifestyle Limitations and Restrictions
# Average Teen Stressors vs. Teen with Chronic Disease

<table>
<thead>
<tr>
<th>Average Teen Stressors</th>
<th>vs.</th>
<th>Teen with Chronic Disease</th>
</tr>
</thead>
<tbody>
<tr>
<td>School</td>
<td></td>
<td>Insurance Coverage</td>
</tr>
<tr>
<td>Dating and Friendships</td>
<td></td>
<td>Medication Compliance</td>
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<tr>
<td>Peer Pressure</td>
<td></td>
<td>High Risk behaviors</td>
</tr>
<tr>
<td>Body Image</td>
<td></td>
<td>Activity Restrictions</td>
</tr>
<tr>
<td>Puberty</td>
<td></td>
<td>Diet Restrictions</td>
</tr>
<tr>
<td>Family /Peer Conflicts</td>
<td></td>
<td>Traveling Risks</td>
</tr>
<tr>
<td>Bullying</td>
<td></td>
<td>Oral Hygiene</td>
</tr>
<tr>
<td>Family Obligations</td>
<td></td>
<td>Disease Trajectory</td>
</tr>
<tr>
<td>Traumatic Events</td>
<td></td>
<td>Urgent vs. Emergent Signs</td>
</tr>
</tbody>
</table>
EDUCATION + INDEPENDENCE

• Provide education and opportunity for questions (Teach back)
• Utilizing their resources
• Coping skills education
• Encourage patient to ask their physician for clarification
• Insurance education (Name, Type, Coverage Limitations)
• Health App
• My Chart
## DEVELOPMENTAL CHALLENGES AND HEALTHCARE SKILLS

**Table 1**

Neurological, Developmental and Psychosocial Challenges Which Occur With Increased Frequency in Children, Adolescents and Young Adults Born With Critical Congenital Heart Disease

- Stroke
- Seizures
- Abnormal brain morphology and functional connectivity (MRI)
- Abnormal brain growth, cerebral atrophy (CT, MRI)
- CNS hemosiderin deposition (MRI)
- Oral-motor dysfunction
- Poor head control
- Delayed gross and fine motor milestones
- Apraxia of speech
- Clumsiness
- Problems with visual-spatial-motor integration
- Inattention and hyperactivity
- Cognitive impairment
- Impaired memory
- Autism spectrum disorders
- Social awkwardness/Impaired social cognition
- Anxiety
- Depression

Legend: CNS = Central Nervous System; CT = Computerized Tomography; MRI = Magnetic Resonance Imaging

Wernovsky G. Current insights regarding neurological and developmental abnormalities in children and young adults with complex congenital cardiac disease. Cardiol Young. 2006;16(Suppl 1):92–104.
HEALTHCARE SKILLS AND RESOURCE IDENTIFICATION

- Assessing skills
- When are specialists are needed and making referrals
- Appointments and MyChart
- EMR communication
- Other technologic advances
SKILLS/ASSESSMENTS

PEDIATRIC CARDIOLOGY | TRANSITION MEDICINE PROGRAM

MY HEART KNOWLEDGE

Please check the box that applies to you right now.

1. I know the medical name of my CHD (congenital heart defect), my cardiac characterization history, and surgical repairs (if any).
2. I understand the risks and potential complications associated with my heart condition and the need for future follow-up.
3. I understand the importance of regular check-ups and routine medical care.
4. I understand the role of medication in managing my heart condition.
5. I understand the potential side effects of medications and how to report any changes.
6. I understand the importance of maintaining a healthy lifestyle to support heart health.
7. I understand the importance of regular exercise and physical activity.
8. I understand the role of diet and nutrition in managing heart health.
9. I understand the importance of regular dental check-ups and the impact of oral health on heart health.
10. I understand the importance of stress management and mental health in supporting heart health.

Sample Transition Readiness Assessment for Youth/Young Adults
Six Core Elements of Healthcare Transition 2.0

Transition and Self-Care Importance and Confidence

On a scale of 1 to 10, please circle the number that best reflects how you feel right now.

1. I feel confident about managing my own healthcare.
2. I feel confident about managing my own medications.
3. I feel confident about communicating with healthcare providers.
4. I feel confident about making decisions about my healthcare.
5. I feel confident about making decisions about my medications.

My Health

Please check the box that applies to your situation.

1. Yes, I need to learn how to do this...
2. Yes, someone needs to do this...
3. No, I don't need to do this...

Using Health Care

1. I can explain my medical needs to others.
2. I can explain my medical history to others.
3. I can explain my medical medications to others.
4. I can explain my medical appointments to others.
5. I can explain my medical insurance to others.

TRANSITION Q

PLEASE ANSWER THESE QUESTIONS ON YOUR OWN

Self-Management Skills: These questions are about being in charge of your health.

For each question, please circle only 1 answer.

1. I answer a doctor's or nurse's question... Never
2. I help make decisions about my health... Sometimes
3. I am in charge of taking my medication... Always
4. I talk to a doctor or nurse when I have health concerns... Never
5. I book an appointment when I have a question about my health... Sometimes
6. I talk about my health conditions to people when I need to... Always
7. I ask the doctor or nurse questions... Sometimes
8. I speak to the doctor instead of my parents or guardians... Never
9. I communicate my medical history when I am asked to... Sometimes
10. I contact a doctor when I need to... Never
11. I see the doctor or nurse on my own during an appointment... Sometimes
12. I ask for advice or assistance when I need it... Always
13. I attend my own doctor's appointments... Sometimes
14. I book my own doctor's appointments... Always

CanChild

Texas Children's Hospital

Baylor College of Medicine
NEW TOOLS...

Instruction for the REALM-TeenS

An examiner provides the list of words to an adolescent in a private setting.

The examiner asks the youth to read each word aloud beginning with the first word.

If they struggle with a word, the examiner can suggest they move to the next word they recognize.

Dictionary pronunciation is the scoring standard.

The examiner counts a word as correct if the word is pronounced correctly and no additions or deletions have been made to the beginning or ending of the word.

For example, a patient who says “adolescence” would not receive credit for the word “adolescent.”

Words pronounced with a dialect or accent are counted as correct provided there are no additions or deletions to the word.

If a patient indicates that he/she knows the meaning of the word, but is unable to say it, no credit is given.

<table>
<thead>
<tr>
<th></th>
<th></th>
<th>Y</th>
<th>N</th>
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</thead>
<tbody>
<tr>
<td>1</td>
<td>Diabete s</td>
<td>Y</td>
<td>N</td>
</tr>
<tr>
<td>2</td>
<td>Exercise</td>
<td>Y</td>
<td>N</td>
</tr>
<tr>
<td>3</td>
<td>Prevention</td>
<td>Y</td>
<td>N</td>
</tr>
<tr>
<td>4</td>
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<td>Y</td>
<td>N</td>
</tr>
<tr>
<td>5</td>
<td>Nausea</td>
<td>Y</td>
<td>N</td>
</tr>
<tr>
<td>6</td>
<td>Fatigue</td>
<td>Y</td>
<td>N</td>
</tr>
<tr>
<td>7</td>
<td>Adolescent</td>
<td>Y</td>
<td>N</td>
</tr>
<tr>
<td>8</td>
<td>Anemia</td>
<td>Y</td>
<td>N</td>
</tr>
<tr>
<td>9</td>
<td>Tetanus</td>
<td>Y</td>
<td>N</td>
</tr>
<tr>
<td>10</td>
<td>Bronchial</td>
<td>Y</td>
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Scoring the REALM-TeenS

Raw Score - Reading Level

Scoring the REALM-TeenS

Raw Score - Reading Level

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<td>10</td>
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<td>Y</td>
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</tr>
</tbody>
</table>

Short Grit Scale

Please respond to the following 8 items.

Be honest – there are no right or wrong answers!

1. New ideas and projects sometimes distract me from previous ones.*

   □ Very much like me
   □ Mostly like me
   □ Somewhat like me
   □ Not much like me
   □ Not like me at all

2. Setbacks don’t discourage me.

   □ Very much like me
   □ Mostly like me
   □ Somewhat like me
   □ Not much like me
   □ Not like me at all

3. I have been obsessed with a certain idea or project for a short time but later lost interest.*

   □ Very much like me
   □ Mostly like me
   □ Somewhat like me
   □ Not much like me
   □ Not like me at all

4. I am a hard worker.

   □ Very much like me
   □ Mostly like me
   □ Somewhat like me
   □ Not much like me
   □ Not like me at all

5. I often set a goal but later choose to pursue a different one.*

   □ Very much like me
   □ Mostly like me
   □ Somewhat like me
   □ Not much like me
   □ Not like me at all

6. I have difficulty maintaining my focus on projects that take more than a few months to complete.*

   □ Very much like me
   □ Mostly like me
   □ Somewhat like me
   □ Not much like me
   □ Not like me at all

7. I finish whatever I begin.

   □ Very much like me
   □ Mostly like me
   □ Somewhat like me
   □ Not much like me
   □ Not like me at all

8. I am diligent.

   □ Very much like me
   □ Mostly like me
   □ Somewhat like me
   □ Not much like me
   □ Not like me at all

Texas Children's Hospital

Baylor College of Medicine
REFERRAL RESOURCES

Transition Team
DK Lovick BSN RN CCCTM
Nicole Broussard LCSW

Medical Legal Partnership
Tom Mendez – JD
Social worker

Subspecialty referrals during transition:
Jennifer Dietrich MD (Gyn)
Waqar Qureshi MD (GI)
James Schwartz MD (GI)
Sussman MD (Liver)
Khaderi MD (Liver)
★Katherine E. Cutitta, PhD (Psy)
NEW RESOURCE

Cardiac Psychologist - Dr. Katherine Cutitta

- Behavioral Activation
- Adherence to Medication
- Adherence to Nutrition Recommendations
- Adjustment to Cardiac Diagnosis
- How to Talk to Peers about Diagnosis
- Family Conflict with Disease Management
- Adherence to Activity Limitations / Recommendations
- ICD/PM Device Education and Anxiety Mgmt.
- Transition to Independence with Disease Mgmt.
MEDICAL LEGAL PARTNERSHIP

What is Texas Children’s Medical-Legal Partnership (MLP)?
- Addresses legal needs for vulnerable, low-income populations
- Staff/volunteer attorneys provide free legal advice to patient families:
  - Improving housing conditions
  - Obtaining guardianship and alternatives to guardianship
  - Securing public school accommodations for children with disabilities
  - Social Security denials or delays

Who Qualifies?
- Any family referred by a TCH social worker will receive free legal consultation regardless of income
- Direct legal representation provided for low income families
- Counties served directly by MLP lawyers are Harris, Montgomery, Liberty, Chambers, Galveston, Brazoria, Fort Bend, and Waller
OUTLINE

• Increasing numbers of youth with chronic disease
• Transition vs. transfer
• Transition: stakeholders and establishing standard of care
• The adolescent brain
• Concerns/deficiencies in adolescents with chronic disease

• Cardiology strategies to connect and improve transition
  - Teens
  - Providers
More Time with Patients and Shared Decision-Making Are the Most Effective Patient Engagement Initiatives

What are the top two initiatives that are most effective at improving patient engagement?

- Have physicians, nurses, or other clinicians spend more time with patients: 59%
- Shared decision-making: 54%
- Make it easier for patients to access relevant services: 36%
- Work with health plans to provide incentives for patients to improve their health: 24%
- Give patients more information about their conditions: 23%
- Remote monitoring using wireless devices/wearables: 5%

Base = 340 (Multiple responses)
NEJM Catalyst (catalyst.nejm.org) © Massachusetts Medical Society
DEDICATED TRANSITION VISITS

Knowledge, Skills, & Ability + Willingness to Manage Health = Shared Decision Making = IMPROVED HEALTH OUTCOMES
Motivational Interviewing is key!
INSTRUCTIONAL CONVERSATION
*Teaching through Dialogue!*

- Increase patient activation and engagement
- One-on-one with patient → teach back to family
- Clear goals → Individualized Learning Plans
- Help patients make and reach self-management goals
- Question patients about their knowledge, current healthcare skills, daily life, trajectory of disease
- Build confidence toward independence in one's healthcare
### Comprehensive Heart Health Activation Tool for Transition...

**Your Three Sentence Summary** helps you communicate your heart condition to others. Let’s practice!

- My name is __________________________, and I am ___ years old.
- I was born with or have _______ congenital heart defect or arrhythmia ____________________.
- and was repaired or am currently managed with surgery, catheterization, medications or lifestyle ____________________.

I am currently feeling the following emergent or urgent symptoms:
- [✓] chest pain
- [✓] shortness of breath
- [✓] dizzy, lightheaded, syncope, palpitations

**My meds are:**
- [✓] ___________
- [✓] ___________
- [✓] ___________
- [✓] ___________
- [✓] ___________

I __do/don’t____ need antibiotics before I go to the dentist.

- Having good oral hygiene is important for my heart health!
- Avoiding high risk behaviors is also important! What are high risk behaviors to you: smoke etoh pierce tats sex drugs________.
- Some CHD patients have traveling risks as well; what do you need to know about traveling: altitude, meds, nearest ER________.

**What will my disease look like in the future? Do I need surgery, caths, or just monitoring? Will I pass this on to my kids?**

My doctor and I have discussed the following possible long term issues associated with my heart condition:
- [✓] ___________
- [✓] ___________
- [✓] ___________

These are the things I need to do every year to protect my heart:
- [✓] see my cardiologist
- [✓] visit the dentist
- [✓] get a flu shot

My risk of passing on my heart condition to my children is:
- low, medium, high__________.

If I become pregnant or want to become pregnant I should talk to my cardiologist right away!

As an adult with a CHD, I will need to know about:
- Advance Directives are ______ my wishes ________.
- My insurance is ___________________ and I am covered until I am ________.
- My plan for continued coverage includes: ____________________

_________education and occupational needs_________.
CHHATT is intended for serial use

✓ **STEP 1** - Three Sentence Summary

✓ **STEP 2** - Basic Management

✓ **STEP 3** - Trajectory and Lifelong Management
Your Three Sentence Summary helps you communicate your heart condition to others. Let's practice!

My name is ____________________________________________, and I am ____ years old.

I was born with or have ____________________________ congenital heart defect or arrhythmia ____________________________.

and was repaired or am currently managed with ____________________________ surgery, catheterization, medications or lifestyle ____________________________.

I am currently feeling the following emergent or urgent symptoms:

✓ chest pain
✓ shortness of breath
✓ dizzy, lightheaded, syncope, palpitations
<table>
<thead>
<tr>
<th>GOOD FOR ME</th>
<th>BAD FOR ME</th>
</tr>
</thead>
<tbody>
<tr>
<td>Activities</td>
<td>Restrictions</td>
</tr>
<tr>
<td>Diet</td>
<td>Avoid</td>
</tr>
<tr>
<td>Coping Skills</td>
<td>Red Flags</td>
</tr>
</tbody>
</table>

My meds are: I take them for: [ ] do/don’t need antibiotics before I go to the dentist.

Having good oral hygiene is important for my heart health!

Avoiding high risk behaviors is also important! What are high risk behaviors to you: smoke, etoh, pierce, tats, sex, drugs.

Some CHD patients have traveling risks as well; what do you need to know about traveling: altitude, meds, nearest ER.
<table>
<thead>
<tr>
<th>What will my disease look like in the future? Do I need surgery, caths, or just monitoring? Will I pass this on to my kids?</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>My doctor and I have discussed the following possible long term issues associated with my heart condition:</strong></td>
</tr>
<tr>
<td>✓</td>
</tr>
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<td><strong>As an adult with a CHD, I will need to know about:</strong></td>
</tr>
<tr>
<td>Advance Directives are <strong>my wishes</strong>.</td>
</tr>
</tbody>
</table>
| My insurance is **My insurance coverage is** and I am covered until I am ____.
| My plan for continued coverage includes: **My plan for continued coverage includes** education and occupational needs. |
TRACKING OVERALL PROGRESS

Survey Results
- Overall Understanding of CHD Knowledge: K-Tool Risk Stratification
- Overall Managing Healthcare Skills: Q-Tool Risk Stratification
- Stage of Change in Transition Education
- Level of Engagement in Transition Education
- Post-Education Assessment of Saturation

Summary

TCT Visit Note

Transition Team Recommendation

Expected Return

Form Status

Complete?

No Evidence of Learning
- Needs Reinforcement
- Indicates Understanding
- Demonstrates with Supervision
- Demonstrates Independently

D/C pathway
- HOLD transition
- CONT standard education
- CONT abbreviated education
- CONT education with accommodations
- PARENT track

TRANSFER appropriate or completed

Relapse (return to older behavior / abandonment of new change)
- Pre-Contemplation (not acknowledging behavior needs change)
- Contemplation (acknowledging need for behavior change but not ready or sure of wanting change)
- Preparation/determination (getting ready to change)
- Action/Willpower (changing behavior)
- Maintenance (continuing new behavior)

Defiance (refuse to acknowledge need or receive education)
- Passivity (hearing and observing but distracted)
- Compliance (acceptance, minimal effort, lack retention)
- Reflection (answer questions, linking knowledge, discussing)
- Curiosity (asking questions, critically thinking, proactive, persistence)
COMMUNICATION WITH PROVIDERS
TRANSITION ADVOCACY

Sample listing of CPT codes related to transition

- 99241-99245  Office or other outpatient consultations
- 99339, 99340  Care plan oversight services
- 99366-99368  Medical team conference
- 96160, 96161  Health risk assessment (eg., transition readiness/self-care assessment)
- 99441-99443  Telephone services
- 99444  Online medical evaluation
- 99446, 99449  Inter-professional telephone/Internet assessment and management services
- 99487, 99489  Complex chronic care management services
- 99490  Chronic care management services
- 99495, 99496  Transitional care management services
- 99660-99862  Education and training of patient self-management services

https://www.gottransition.org/resourceGet.cfm?id=352
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  - Providers

• Everyone can help transition adolescents w chronic dz
HOW EVERYONE CAN HELP

• Integrate transition skills into practice

• Inpatient + outpatient opportunities

• Research, QI and database creation
NURSING TRANSITION INTEGRATION

Engage
- Identify deficits
- Agree on goals

Educate
- Seek opportunities
- Encourage proactive

Evaluate
- Reinforce education
- Praise progress
SW TRANSITION INTEGRATION

Engage
- Encourage Independence
- Identify Needs

Educate
- Resources
- How to Access

Evaluate
- Effective Follow-Up
- Praise Efforts
PHYSICIAN TRANSITION INTEGRATION

Engage

- Allow teens to ask questions
- See adolescent independently
- Engage your stakeholders to be on board with transition

Educate

- Teach about disease process
- Educate parents about the importance of independence
- Discuss mental health and lifelong concerns

Evaluate

- Determine what is needed prior to transfer
- Evaluate the need for other subspecialists
- Determine where adult care will be performed
REALISTIC TRANSITION...

what people think it looks like
what it really looks like
Questions?