# Transitioning the Adolescent Transplant Recipient from Pediatric to Adult Transplant Care

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UAB MEDICINE PEDIATRICS

## Disclosures

- No financial disclosures

## Objectives

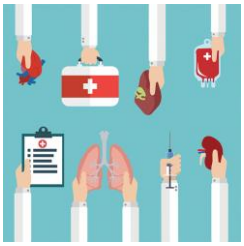
At the end of this presentation, participants should be able to:

- Define healthcare transition
- Describe 2 stakeholders in transition
- Describe transition readiness measurement
- Identify resources for information regarding healthcare transition

## Introduction

Transplantation has become standard of care for pediatric patients with solid-organ failure

- Improved success rates
  - advances in surgical and organ preservation techniques
  - improved immunosuppressive and antiviral regimens
  - changes in donor allocation



## Introduction

- 20 year survival rates for pediatric recipients:
  - Kidney 86.1%
  - Liver 58.5%
  - Heart 61.4%

## Introduction

- Survival into adulthood = transition to adult transplant care
  - Often a lack of structured preparation to guide transition:
    - Limitations in health and well-being
    - Decreased treatment/medication adherence
    - Patient dissatisfaction
    - Higher ED/hospital use
    - Higher costs of care

## Introduction

- Well planned transition from pediatric to adult transplant care:
  - Patient-reported satisfaction with care
  - Increased self-management
  - Improved empowerment

## Concepts of Transition

- **Transition**: A movement, development or evolution from one form, stage, or style to another
- **Medical Transition**: The process of moving from a pediatric system to an adult system
- **Transfer**: The actual point in time (event) when responsibility for patient care is "handed off" to an adult provider

## Concepts of Transition

- **Health Care Transition (HCT):**
  - Address medical, psychosocial, educational and vocational needs
  - Developmentally appropriate, coordinated, and comprehensive
  - Promote communication, self-advocacy and self-care skills
  - Transfer should not occur until recipient can demonstrate health care independence***

## Transition Stakeholders

- Adolescent transplant recipient
- Parent/Caregiver
- Pediatric Transplant Team
- Adult Transplant Team
- Healthcare system

## The Adolescent SOT Recipient

- Struggle with consequences of transplantation on the medical, physical, emotional, and social aspects of their lives
- Must learn to self manage medical care in addition to other responsibilities
- Often have difficulty adjusting to increased level of autonomy
- Can view transition as rejection

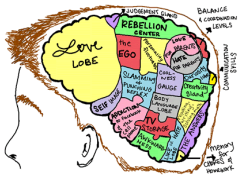


## The Adolescent SOT Recipient

- Medication adherence
  - 30-76% non-adherence/non-compliance rates
  - Associated with rejection, poor quality of life, increased health care costs, and death
  - Heart transplant recipients- 56% mortality rate within 2 years of more than 2 non-adherence episodes

## The Adolescent SOT Recipient

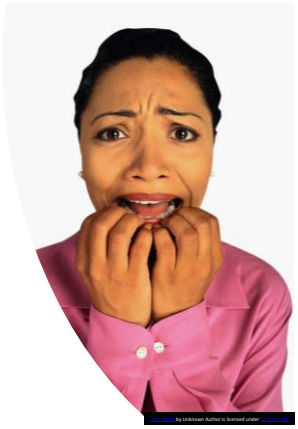
- Barriers to adherence
  - Medication-related
  - Psychological
  - Cognitive
  - Socio-economic






## The Parent/Caregiver

- Transplant medical regimen can cause stress on the family
- Often feel sense of loss or guilt
- Struggle with role change
- Often reluctant to encourage developmentally appropriate activities that promote independence
- Fearful about the prospect of transitioning
- View transition as abandonment
- Barrier to successful transition





## The Pediatric Transplant Team

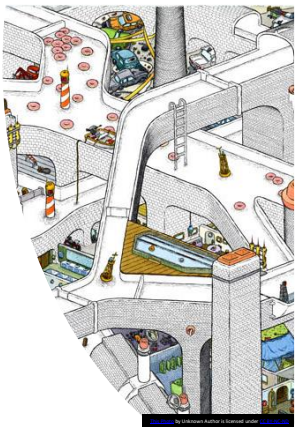
- Investment in patients
  - Personal
  - Programmatic
    - Survival statistics
- Fearful of medical consequences of increase adolescent autonomy
- Perception that patient will not receive the same level of care

## The Adult Transplant Team

- Adult Transplant Teams
  - Lack training in developmental/behavioral aspects of adolescent medicine
  - Disease centered care vs. family centered care
  - Lack of resources for young adult issues

## The Healthcare System

- Coordination of services/records
- Insurance coverage
  - Eligibility based on age
  - Loss of coverage is a predictor of allograft loss in pediatric kidney transplant recipient
- Reimbursement
- Personnel




## Status of Transition Preparation in the US

- 2016 National Survey of Children's Health
  - Transition preparation for 83% of youth with special health care needs (SHCN) do not meet the national HCT performance measure
- 2020-2021 National Survey of Children's Health
  - Transition preparation for 84% of youth with SHCN and 80% of youth without SHCN do not meet the national HCT performance measure

## Status of Transition Preparation in the US

- OPTN/UNOS Pediatric Transplantation Subcommittee surveyed pediatric kidney/liver programs Jan-Feb 2018
  - Lack of understanding of terms “transition” and “transfer”
  - Not all programs had formalized transition processes
  - Age is determining factor
  - Reluctance to transfer on the part of the parents were associated with higher lost to follow-up rates
  - Transplant coordinators were most frequently the individuals responsible for contacting providers for transfer
  - Physicians at small volume transplant centers are more frequently involved in the transfer discussion

## Evidence Base

- Previously limited evidence base on HCT outcomes
  - Systematic review done between January 1995 and April 2016-
    - Small of amount of studies report statistically significant positive outcomes
      - Improvement in adherence to care
      - Improved perceived health status, quality of life, and self-care skills
      - Increased adult visit attendance
      - Less time between last pediatric and initial adult visit
      - Few studies examined cost/cost savings
      - Concluded that lack of detailed descriptions of transition interventions made it difficult to link specific interventions to outcomes

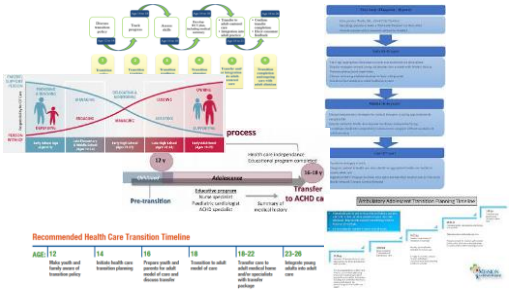
## Evidence Base

- Evidence base on HCT outcomes is growing
  - Updated systematic review done between May 2016 and December 2018
    - 84% of articles included found statistically significant positive outcomes resulting from structed HCT
      - Transfer assistance
      - Transition planning
      - Integration into adult care

## Transition Preparation Goals

"The goal of transition in health care for young adults with special needs is to maximize lifelong functioning and potential through the provision of high quality, developmentally appropriate health care services that continue uninterrupted as the individual moves from adolescence into adulthood."

## Transition Preparation




## Transition Preparation

GotTransition.org

- www.gottransition.org
- Maternal and Child Health Bureau and The National Alliance to Advance Adolescent Health
- "6 Core Elements of Transition"
  - Transition Policy
  - Transition Tracking and Monitoring
  - Transition Readiness
  - Transition Planning
  - Transfer of Care
  - Transfer Completion


## Assessing Transition Readiness

- "Transition readiness": indicators that the adolescent and their medical support system (family and medical providers) can begin, continue and finish the transition process through transfer
- Involves multiple components, is measurable and is potentially modifiable prior to transfer
- Assessing readiness is essential to identifying targets for transition intervention, assessing outcomes of transition interventions, tracking progress of readiness over time

Schwartz, L., et. Al (2014). Measures of readiness to transition to adult health care for youth with chronic physical health conditions: A systematic review and recommendations for measurement testing and development. *Journal of Pediatric Psychology, 39*(6), 588-601

## Assessing Transition Readiness

- Transition Readiness Assessment Questionnaire (TRAQ)
- 20 item- "Managing Medications," Appointment Keeping," "Tracking Health Issues," "Talking with Providers," and "Managing Daily Activities"

Source: http://www.ncbi.nlm.nih.gov/pubmed/24976354

## Transition Preparation at COA

PROGRAM COMPONENTS

- Transition Policy
- Transition Registry
- Transition Preparation
- Readiness Assessments
- Transfer of Care Packets

## Transition Preparation at COA

Transition Policy

- Commitment to successful transition
- Goal age range for transfer of care
  - 18-20, hard deadline age 23
- Patient/parent expectations for transition preparation
- HIPAA, confidentiality, privacy, etc.
- Provided at time of referral for transplant evaluation
- Provided at age 12

## Transition Preparation at COA

Transition Registry

- Process for identifying and tracking transitioning patients
  - Receipt of policy, binder, etc.
  - Stages of transition preparation
  - Adult clinic appointment details

## Transition Preparation at COA

Transition Binder

- Policy
- Provider contact information
- Quick reference guides
- Medical history
- Medications
- Appointments
- Transition planning
- Education
- Caregiver resources

## Transition Preparation at COA

Transition Checklists

- Age/developmentally appropriate
- Stage 1-5
- Builds on skills of previous stages


## Transition Preparation at COA

Encouraging independence

- Clinic visits without parent/caregiver (Time Alone)
- Co-signing consents
- Encourage adolescents to contact coordinators



## Transition Preparation at COA

Assessing Readiness

- Transition Readiness Assessment Questionnaire (TRAQ)
- Patient version and caregiver version
- Completed at yearly visit

## Transition Preparation at COA

Transition Follow-up

- Patient follow-up surveys post transfer of care
- Pediatric to Adult team communication




## Transition Resources

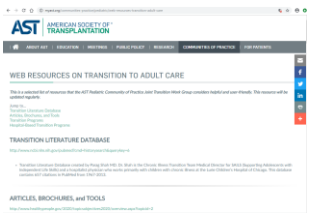
- GotTransition.org
  - 6 Core Elements of Healthcare Transition™
    - downloadable
  - Resources for health care providers and youth


## Transition Resources

- American Society of Transplantation (AST)

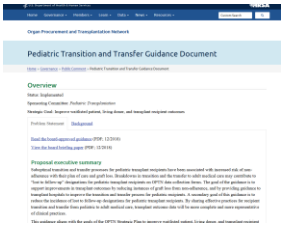
https://www.myast.org/communities-practice/pediatric/web-resources-transition-adult-care

- Transition Literature database
- Articles, Brochures and Tools
- Transition Programs



# Transition Resources

- Organ Procurement and Transplantation Network (OPTN)
  - "Pediatric Transition and Transfer Guidance Document"




https://optn.transplant.hrsa.gov/governance/public-comment/pediatric-transition-and-transfer-guidance-document/

# Questions?

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