

# Transitioning from Youth to Adult Post Transplant: Preparing Patients to be “Good 2 Go”

Ruta Niedra, MSW, RSW  
Labatt Family Heart  
Centre/Transplant  
Centre

Khush Amaria, PhD, C.Psych  
Good 2 Go Transition Program  
Division of Adolescent  
Medicine

The Hospital for Sick Children  
Toronto, Canada

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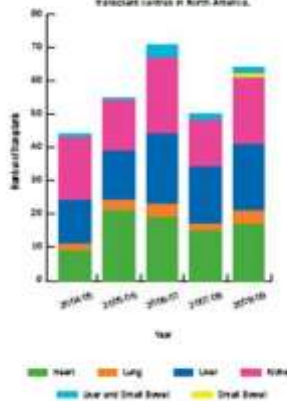
## Multi-Organ Transplant Program

Total transplants to date: 1422  
Patients actively followed: 345



### Clinical Activity Report

**GRAND TOTAL/ACTIVITY**  
SickKids remains one of the top 5 transplant centers in North America.



## Good 2 Go Transition Program

- Goal: To prepare all youth with chronic health conditions to leave SickKids by age of 18 years with the skills to:
  - Advocate for themselves (or through others)
  - Maintain health-promoting behaviors
  - Utilize adult healthcare services appropriately and successfully
- Transition from family-centred to patient-centred care facility



## Objectives for Presentation

- Identify the difference between transition and transfer
- Examine the purpose of early and ongoing preparation for transitioning and the “limits” of the teen brain
- Review ISHLT guidelines for the care of (heart) transplant patients
- Introduce four perspectives of the transitioning transplant patient



## Transition vs. Transfer

- Transition is a process of *growing up ready* for adult life. A purposeful, planned movement of youth with special health care needs from child-centered to adult-oriented care
- Transfer is a one time event

Pediatric Health Care

Adult Health Care

**Good 2 Go Transition Work**



Transfer of care = point in time

(Blum, 1993; Rosen, 2003)



## What's All the Fuss About?

- Increased survival rates – extended lifespan of youth with special health care needs (SCHN) into adolescence and adulthood
- Evidence that transfer of care is “risky”, yet guidelines on evidence-based preparation are still in development
- Different cultures of pediatric and adult healthcare systems
- Multiple stakeholders – one of which has a TEEN brain



## Challenges to Preparing... Post-transition Outcomes

- Transfer of care is often problematic and carries risk of:
  - Health care drop-out (voluntary or by default)
  - Poor treatment adherence to plans and medications
  - Increases in illness states and relapses
  - Increases in ER visits and hospitalizations
  - Poor overall health outcomes (increased morbidities and mortalities)
  
- Converging evidence from multiple sources, for example:
  - General adolescent research (Sawyer, Blair & Bowes, 1996)
  - Diabetes (Frank, 1996; Nakhla et al, 2008)
  - Congenital Heart Disease (Reid et al, 2004)
  - Hydrocephalus (Tomlinson & Sugarman, 1995)
  - Renal transplant (Watson, 2000)
  - Liver transplant (Annunziato et al, 2008)



## Challenges to Preparing... Post-transition Outcomes

- Prevalence and correlates of successful transfer from pediatric to adult health care among a cohort of young adults with complex congenital heart defects (Reid et al, 2004)
  - 53 % of patients with congenital heart disease did not successfully transfer to adult care within the recommended timeframe
  
- Perceptions of transition care needs and experiences in pediatric heart transplant recipients (Anthony et al, 2009)
  - Lack of information and misperceptions
    - Teen's apathy and parents anxiety/fear
    - Negative perception of the quality of adult care (vs paediatric)



## Challenges to Preparing... Different Cultures

Paediatric System	Adult System
<ul style="list-style-type: none"> <li><input type="checkbox"/> Family-centered</li> <li><input type="checkbox"/> Fewer patients</li> <li><input type="checkbox"/> Physically appropriate for children</li> <li><input type="checkbox"/> Multi-disciplinary team and supports are readily available</li> </ul>	<ul style="list-style-type: none"> <li><input type="checkbox"/> Individually-centered</li> <li><input type="checkbox"/> Large # of patients</li> <li><input type="checkbox"/> Physically appropriate for adults</li> <li><input type="checkbox"/> Limited team and resource support</li> <li><input type="checkbox"/> HCPs may have limited exposure to paediatric specific conditions</li> </ul>



## Challenges to Preparing... Multiple Stakeholders

Youth	Parents
<ul style="list-style-type: none"> <li><input type="checkbox"/> Feeling unprepared</li> <li><input type="checkbox"/> Sad</li> <li><input type="checkbox"/> Apprehension about adult system</li> </ul>	<ul style="list-style-type: none"> <li><input type="checkbox"/> Feeling worried that the adult system will not care for their child</li> <li><input type="checkbox"/> Feelings of abandonment</li> <li><input type="checkbox"/> Reluctant to let go of paediatric system</li> </ul>
Pediatric HCPs	Adult HCPs
<ul style="list-style-type: none"> <li><input type="checkbox"/> Difficulty "letting go"</li> <li><input type="checkbox"/> Worry teen will drop out of system</li> <li><input type="checkbox"/> Fear that teen does not have necessary skills for the adult system</li> </ul>	<ul style="list-style-type: none"> <li><input type="checkbox"/> Youth lack responsibility</li> <li><input type="checkbox"/> Frustration and concern</li> <li><input type="checkbox"/> Helpless</li> </ul>

## Challenges to Preparing... The Teen Brain

- Teen brain is in development
  - Adolescent functioning
    - Identity formation, independence, risk-taking



## Challenges to Preparing... Adolescence!

- Time of change
- Time of growth and development
- Time of questioning and discovery
- Results in exploration and dealing with the consequences



## Adolescence: Developmental Tasks

- Independence
  - Hallmark
  - Testing limits
- Body Image
  - Focus on looks/weight
- Peer Group
  - Fitting in/rejection
  - Social skills
- Identity
  - Ego
  - Sexual
  - Vocation/Education



## Challenges to Preparing... The Teen Brain

- Teen brain is in development
  - Adolescent functioning
    - Identity formation, independence, risk-taking
- Executive functioning
  - In development



## The Teen Brain: Under Construction



- Rapid increase in intellectual ability from childhood to adolescence
- Temporal and parietal region
  - Teen = Adult
- Frontal lobe development (prefrontal cortex) continues into 3rd decade
  - “Executive Functioning”
    - Organizing
    - Planning
    - Regulating emotion
    - Attention
    - Impulse control



## Challenges to Preparing... The Need to Start Early

- Principles of transition:
  - Start Early!
  - Collaborative (Shared Management Approach)
  - Progressive movement towards increasing participation in health management





## Shared Management Model

Age & Time ↓	Provider	Parent/Family	Youth
		→	
	Major responsibility	Provides care	Receives care
	Support to Parent/family & child/youth	Manages	Participates
	Consultant	Supervisor	Manager
	Resource	Consultant	Supervisor/CEO

(Kieckhefer & Trahms, 2000)



## Preparing for Transitions... General Guidelines

- Start Early! Form a team!
- Planned and coordinated approach
- Transition planning occurs at youth's pace
  - Medical stability, cognitive ability, severity of illness, personal goals and social supports, independence...
- Correct misconceptions and cultivate positive attitudes to adult healthcare
- Consider a face-to-face transfer event *before* transition to adult HCPs
- When possible, seek resources and support of the multi-dimensional "transitions" occurring in parallel for the transitioning patient



## Preparing for Transitions for the Youth with Transplant

- ISHLT Guidelines for the Care of Heart Transplant Recipients (2010); Task Force 3: Long-term care of heart transplant recipients

Topic 18

- Psychological Issues Particularly Related to Adherence to Medical Therapy in Heart Transplant Recipients

Topic 19

- Management of the Transition from Pediatric to Adult Care After Heart Transplantation

Topic 20

- Principles of Shared Care After Heart Transplantation



## Preparing for Transitions for the Youth with Transplant

### Topic 20: Shared Care

- Effective communication
- Pre-transplant period
  - Decisions about ongoing interim care
- Post-transplant period
  - Awareness of changes in medical condition
- A coordinated role of all HCPs that are recognizable by the patient

### Recommendations

- Ensure bidirectional contact between transplant and referring team (phone #s, emails)
- Share appointment times and plans
- Formal procedures for results to be shared



## Preparing for Transitions for the Youth with Transplant

### Topic 18: Adherence

- 17.8%: Non-adherence to immunosuppressive medication, smoke, excess alcohol, fail to complete diagnostic tests, not follow diet, not exercise...
- Even higher rates in pediatric heart transplant recipients, especially during adolescence
  - E.g., 46% non-adherence to the immunosuppressive regimen

### Recommendations

- Routine adherence assessment from multiple sources (child and parent-report, clinical judgment, drug levels) and discussion of barriers to adherence
- Incorporate strategies to increase maturity and self-management



## Preparing for Transitions for the Youth with Transplant

### Topic 19: Managing Transitions – Critical Milestones

- Understanding of original cause of organ failure
- Awareness of long- and short-term clinical implications
- Comprehension of the impact of health status on sexual health
- Demonstrating sense of responsibility of self-care

### Recommendations

- Work towards developing and assessing critical milestones
- Simultaneous preparation of parents for transition
- Adult and pediatric HCPs cultivate partnerships
- Ideal adult resources: liaison nurse coordinator, social worker, reproductive specialist



## Case Example: Questions

- What challenges exist as potential barriers to adolescents' successful transition?
- What is your plan of action?
- Who is on your Team? When do you Start? What are your goals?



## Summary

- Transition is a process that should start early
- Transition does not end with transfer to the adult healthcare system
- Developmental and cultural awareness is critical for all stakeholders
- We need to continue to build evidence-based practices to promote healthy transitions in a purposeful and planned way for youth with special healthcare needs



## Contact Information

- Khush Amaria, PhD, C.Psych

416-813-5261

[khush.amaria@sickkids.ca](mailto:khush.amaria@sickkids.ca)

[www.SickKids.ca/Good2Go](http://www.SickKids.ca/Good2Go)

- Ruta Niedra, MSW, RSW

416-813-5883

[ruta.niedra@sickkids.ca](mailto:ruta.niedra@sickkids.ca)

