Lifestyle and Psychosocial Issues: Transition to Adult Care

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Transition to Adult Care

FINANCIAL DISCLOSURE:
No relevant financial relationship exists
The Plan

I. Language matters: the difference between transfer & transition

II. Congenital heart disease as a model to consider the rationale and ‘best practices’ for transition

III. Putting theory into practice: practical strategies to enhance the transition process
Note: We all face transitions

Presentations at AHA 2014:

• Challenges in the Fellow-to-Faculty Transition
• Becoming an independent faculty: How to successfully transition from the early career grant to an R01

Success during these professional transitions requires preparation, education, and coordination... not unlike patient health care transitions
Examples of Health Care Transitions

- “Healthy person” → patient
- Intensive care to the general ward
- Hospital to home (or rehabilitation facility)
- Rehabilitation facility to home
- Acute surgical pain to chronic pain
- Active treatment to palliative care
- Intervention: contemplation → procedure → outcome
- Pediatric to adult health care
Language matters: Transfer vs. Transition
Transfer ≠ Transition

Health Care Transfer = An Event

- Movement of patients (and their medical records) from one location to another
- **Important consideration:** availability of adult providers
When to Transfer?

Flexible age of transfer

- Transition guidelines typically recommend a flexible age of transfer between 18-21 years

Mandatory age of transfer

- Present in some places (eg, in Ontario, Canada, patients transfer at the age of 18 years)
Survey of US Pediatric Cardiologists (n = 257)

<table>
<thead>
<tr>
<th>PERCEIVED BARRIERS TO ACHD OR ADULT-ORIENTED CARE</th>
<th>%</th>
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<tbody>
<tr>
<td>Parent emotional attachment to pediatric provider</td>
<td>87</td>
</tr>
<tr>
<td>Patient emotional attachment to pediatric provider</td>
<td>86</td>
</tr>
<tr>
<td>Lack of qualified adult providers in specialty</td>
<td>76</td>
</tr>
<tr>
<td>Patient emotional/cognitive delay</td>
<td>76</td>
</tr>
<tr>
<td>Provider attachment to family/patient</td>
<td>70</td>
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<tr>
<td>Parent emotional attachment to institution</td>
<td>69</td>
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<tr>
<td>Patient emotional attachment to institution</td>
<td>65</td>
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Fernandes et al, JACC, 2012
Transition = A Process

- Preparation for (and adoption of) increasing responsibility for one’s health care
- Health care management gradually shifts from the parent to the patient
- Goal: “Provide uninterrupted health care that is patient-centered, age and developmentally appropriate, flexible, and comprehensive”

Transfer ≠ Transition

When to Transition?

Begin early with patients
- Adapt to a patient’s physical, developmental and psychosocial maturation
- Never too early to begin educating patients and teaching self-management skills...but ideally begins by 12 years

Engage parents
- Parents should be prepared for (and included in) transition efforts
**Transition Journey**

**PEDIATRIC CARE**
- Family-focused
- Parents as primary decision-makers
- Focus on pediatric health and lifestyle issues

**Can take 5 – 15 years**
- Transfer is ideally one component of transition

**ADULT CARE**
- Patient-focused
- Patients as primary decision-makers
- Focus on adult health and lifestyle issues
Transition Journey

Adolescents & young adults:

• **Taking charge:** As developmentally appropriate, teens gradually begin assuming increased responsibility for their health care management.

Parents:

• **Letting go:** Gradually begin fostering increased independence and responsibility in their children.

Pediatric and adult care providers
Transition Stakeholders

Parents

Pediatric Providers

Adult Providers

PATIENTS
A Model from Congenital Heart Disease (CHD): Best Practices for Transition
The ultimate goal of a transition program is to optimize the quality of life (QOL), life expectancy, and future productivity of young patients.
The Health, Education, and Access Research Trial (HEART-ACHD)

- 12 American Adult CHD centers
- 922 patients ≥ 18 years were recruited at first Adult CHD clinic appointment
- Completed surveys re. gaps/barriers to care

42% reported gaps in care of 3 years or longer
Median age at first gap = 19.9 years
CHD: Lapses in Care

Gaps in Care (%)

- Mild: 59%
- Moderate: 42%
- Severe: 26%

Gurvitz et al, JACC, 2013
If we wait until patients are 16 or 17 to start talking to them about the importance of life-long care, we’ll be too late.
# Lapses in Care: Patient Explanations

<table>
<thead>
<tr>
<th>Feeling well (but know about need for follow-up)</th>
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<tbody>
<tr>
<td>Being unaware that follow-up was required</td>
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<tr>
<td>Told that cardiac follow-up was not required</td>
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<tr>
<td>Discharged from pediatric hospital without identified follow-up medical facility</td>
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<tr>
<td>Complete absence from medical care</td>
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<tr>
<td>Lack of insurance</td>
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<td>Fearful of receiving bad news</td>
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Yeung et al, Int J Cardiol, 2008; Gurvitz et al, JACC, 2013
Upon eventual presentation, patients with lapses in care are more likely to:

- Be symptomatic
- Not have an appropriate medication regimen
- Not have received optimal medical care
- Receive additional diagnoses
- Require additional diagnostic testing
- Require urgent cardiac intervention

Lapses in Care: Consequences

Putting Theory into Practice: Practical Strategies
Identify a Transition Team: Transition ‘Champions’

- Consider a transition coordinator who is the primary contact for patients, family and staff
  - Ideal, but certainly not sufficient
  - More important for multiple staff to be knowledgeable and committed to enhancing transition

- Engage all staff in the transition team
  - Physicians, nurses, allied health professionals
  - Administrative staff
Consider strategies along the transition journey.
BIRTH
25 YEARS
CHILDHOOD
ADOLESCENCE
TRANSFER
EMERGING ADULTHOOD
DIAGNOSIS
25 YEARS
CHILDHOOD
TRANSFER
At diagnosis, parents can be prepared for their children with KD to become adults with KD.
Talking with Parents

Provide honest medical information

- Focus on current needs but allow them to prepare for the future (including eventual transfer of care)

Acknowledge broader impact of KD

- Do not limit discussions to medical implications of KD
- Discuss potential impact on lives of child and family
- Support parents’ celebration of their child’s achievements
Some General Communication Tips...

INSTEAD OF
Do you have any questions or concerns?

TRY
What are your questions and concerns?

INSTEAD OF
Do you understand the information I’m giving you?

TRY
Am I explaining this clearly?
25 YEARS

CHILDHOOD

ADOLESCENCE

TRANSFER

EMERGING ADULTHOOD

DIAGNOSIS

25 YEARS
Beginning by 12-13 years, patients should be helped to gradually develop the knowledge and self-management skills to eventually assume responsibility for their health care management.
Working with Adolescents

Adolescence

- Significant cognitive, emotional, and sexual development
- ‘Identity formation’ is a key feature
- Sense of personal uniqueness
- Sense of invulnerability (the personal fable: that won’t happen to me)
- The time when we begin to transition patients to take increased responsibility for their health care management is also the time when they are most likely to consider themselves invulnerable

Kaufman, Prog Transplant, 2006
Encourage normal socialization

Social factors contribute to psych adjustment

- Speak to patients and parents to ensure that patients are not being inappropriately limited from participation in school and social activities
- Actively encourage social skills development

Encourage age-appropriate independence

- As developmentally appropriate, most teens can transition toward assuming greater responsibility for their health care and general decision-making
Make a Public Commitment

Patients and Parents:
When patients become teenagers, it is our standard practice for them to speak with their cardiologist on their own for part of the visit.
Health Passports

- Portable health summary
- Created with health provider
  - Educates patient
  - Prepares patient to meet new providers (including in emergency situations)

www.sickkids.ca/myhealthpassport
Patient (& Family) Education

- Name & description of KD and other health conditions
- Names of (and ages at) previous interventions
- Name, dose & purpose of medications

Consider a curriculum or checklist in the medical chart

- Long term health expectations
- Importance of life long specialized health care
- Healthy lifestyle guidelines (eg, exercise)
Self-Management Skills

- Speak independently with health providers
- Contact health providers
- Maintain health records & portable health summary
- Schedule & attend medical appointments
- Adhere to medication regimen; request refills
- Know when & how to access mental health services
- Know when & how to access emergency care
- Understand health insurance matters

Kovacs & McCrindle, Nat Rev Cardiol, 2014
Family & Patient Education Events

2nd Annual Heart Disease in Children
Labatt Family Heart Centre Family Conference
May 29th, 2011

5th Annual Toronto Congenital Cardiac Patient Conference
Saturday May 15, 2010
Guidelines recommend a flexible age of transfer, ideally between 18 and 21 years.
Most parents want what’s best for their kids!

- Less than half think their child would be ready to take complete responsibility at 18 years of age
- It can be scary for many parents to let go
- Parental over-involvement is understandable and not uncommon, but can impede children gaining knowledge and self-management skills
- It is important to fully explain the rationale for and challenges and benefits of transition
At SickKids we prepare our patients to graduate to adult care.

Don’t wait until you are 18 to start planning to leave. Talk with your health-care provider.
Preparation for Transfer: Transfer Events/Tours

- For patients and families
- Pediatric and adult providers in attendance
- Adult clinic orientation & tour
- Meet and greet session (including graduate families)

Set the tone...
Celebrate transfer!
Coordinated Transfer of Care: Transfer Documents for Patients & Family
Coordinated Transfer of Care: Clinical Documentation – Closing the Loop

Pediatric Program:
- Provide letter to patients with information about adult care setting
- Provide comprehensive health summary to adult team

Adult Program:
- Send welcome letter to patients
- Copy the pediatric program on the initial visit letter
Coordinated Transfer of Care: Transfer/Transition Clinics

Options:

- Joint clinic attended by pediatric and adult providers
- Clinic in the pediatric setting to focus on education and preparation for transfer
- Clinic in the adult setting to focus on education and adult care expectations

Considerations: personnel & reimbursement
Consider ‘Internal’ Transfer

- Within a pediatric cardiology practice or program, consider ‘transferring’ patients to an adolescent and young adult clinic
- Could have assigned days in which adolescent and young adult patients are scheduled
- Develop links with providers with expertise in management of adult comorbidities

Coordinated Transfer of Care: But what if there is no Adult KD program?
Between 18-25 years, knowledge and self-management skills continue to develop. Focus on decision-making & responsibility becomes prominent.
The Goal: Patients Retained in Care

- Lapses of care may occur in the pediatric setting, but appear most common around the age of transfer
- Multiple factors contribute to lapsed care
- Consequences can be serious

The Goal: Educated and Responsible Patients

- Transition is an extended process (diagnosis–25 yrs), though a major push should begin at 12-13 yrs
- Patient needs: education & self-management skills

Both goals benefit from close collaboration between pediatric and adult providers
Lifestyle and Psychosocial Issues:
Transition to Adult Care

Thank you
Questions?
Comments?