Here Comes the Adult World: Optimizing Health Care Transition for Adolescents with Special Needs

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No disclosures
Objectives

• To share our team’s research experience with respect to transition

• To summarize the evidence-base with respect to transition

• Plant some ideas
Outline

- What is “transition” and why does it matter?
  - Loss to follow-up: who, why, and when
- Transition interventions
  - CHAPTER Studies: 1, 2 and 3
- Knowledge translation
- Future directions
What is “Transition”?  

- **Transition:** 
  - “The purposeful, planned movement of adolescents and young adults with chronic physical and medical conditions from child-centered to adult-oriented health care systems”  
    - Blum et al. *J Adolesc Health*, 2004  
  - Transition is a *process*, not an *event*  

- **Transfer:** is an event  
  - Patient and his/her records move from pediatric to adult care
Why is Transition Important?

• JR: 23 year old male with congenital heart disease (CHD) repaired in infancy, comes to an Emergency Room with dizziness and palpitations
  • Doesn’t know the name of his CHD
  • Thinks he’s “cured”
  • Last seen age 17 in pediatric cardiology, told to attend adult clinic in 1 year but moved to another city after high school, didn’t know how to find an adult clinic and felt OK so didn’t bother
Exponential Growth of Adult CHD Survivors

Marelli AJ et al. *Circulation* 2014
CHD Survival

Moons et al. *Circulation* 2010
Survivors: Complex health needs

- Cardiac morbidity
  - May be clinically silent until too late
- Cardiac death in early-mid adulthood
- Morbidity related to other organ systems
- High rate of health care resource utilization

- 32nd Bethesda conference:
  - Persons with moderate/complex CHD need lifelong follow-up in specialized ACHD centers

Warnes CA JACC 2001
Loss to follow-up

- How big a problem is this?
- At what ages?
- Risk factors?
- How can we mitigate this problem?
Only 47% of young adults with moderate or complex CHD were seen at a Canadian ACHD centre within 3 years of graduating from SickKids

Predictors of ACHD attendance were:
- history of cardiac surgery in childhood
- older age at last pediatric visit
- documentation in chart of need for follow-up

Reid GJ et al. *Pediatrics* 2004
Loss to follow-up during childhood

Mackie AS et al. *Circulation* 2009
Risk factors for loss to follow-up among children and young adults with congenital heart disease

Andrew S. Mackie, Gwen R. Rempel, Kathryn N. Rankin, David Nicholas, Joyce Magill-Evans

- Case-control study using mixed-methods:
  - Medical records review
  - Structured telephone interviews
- Cases: lost to follow-up > 3 years
- Controls: matched by year of birth and CHD lesion
- Risk factors:
  - No documentation in chart of need for follow-up
  - Lower family income
  - No catheterization within past 5 years
  - Lack of awareness of the need for follow-up

Mackie et al. Cardiol Young 2011
Risk factors for loss to follow-up among children and young adults with congenital heart disease

Andrew S. Mackie,1 Gwen R. Rempel,2 Kathryn N. Rankin,1 David Nicholas,3 Joyce Magill-Evans4

Acknowledgement

This study was supported by a Women and Children’s Health Research Institute Innovation Grant that was funded by the Stollery Children’s Hospital Foundation.

Mackie et al. Cardiol Young 2011
U.S. Data

Prevalence and Predictors of Gaps in Care Among Adult Congenital Heart Disease Patients
HEART-ACHD (The Health, Education, and Access Research Trial)

• 992 subjects at 12 adult CHD centers
  • Recruited at 1st presentation to adult clinic
• Mean age at first gap: 19.9 years
• 42%: gap in cardiology care > 3 years
• 8%: gap in care > 10 years
• Clinic location influenced gap in care

Gurvitz et al. JACC 2013
Gaps in care vs. disease severity

Gurvitz et al. JACC 2013
Self-reported reasons for gap in care

• **Most common reasons:**
  • Felt well
  • Did not think they needed follow-up
  • Changed or lost insurance
  • Not receiving any medical care

Gurvitz et al. *JACC* 2013
Colorado:

- 158 adults with moderate or complex CHD
- 63% had a lapse in care of > 2 years since leaving pediatric center
- Most common cited reason: patient had been told “no need for follow-up” (32%)
- Those with lapse of care more likely to require surgical or catheter intervention within 6 months (OR 3.1, p= 0.003)

Yeung et al. *Int J Cardiol* 2008
Barriers to ACHD care

• **Patient and parent factors:**
  - “Thought I was cured”
  - SES; costs related to missed work/ travel to appointments
  - Anxiety about new providers and clinics

• **Provider factors:**
  - Cardiologists with appropriate training

• **System factors:**
  - Proximity of ACHD clinic
  - Insurance issues
Why “Transition” Matters

- Prevalence of CHD in adults is increasing exponentially
- Late complications are common and may be “silent” until too late
- Many patients with moderate or complex CHD fail to attend adult cardiology care
- A lapse in care associated with later cardiac re-intervention
But what are we actually doing to facilitate transition?

- Lots of Position Statements
  - American Heart Association 2011

- Survey of North American and European centers
  - Only 22% of centers had a formal transition program
    
    Hilderson D et al. *Ped Cardiol* 2009

- Only 55% of pediatric cardiologists self-report that they begin transition education <17 years of age
    
    Fernandes SM et al. *JACC* 2012
How do we facilitate transition?

Is there a “gold” standard?
Outline

• What is “transition” and why does it matter?
  • Loss to follow-up: who, why, and when
• Transition interventions
  • CHAPTER Studies: 1, 2 and 3
• Knowledge translation
• Future directions
Knowledge = Confidence

• Unfortunately, most teens and young adults with CHD have limited knowledge of their heart
  
  Van Deyk K, Amer J Cardiol 2010
  Dore A, Can J Cardiol 2002
  Kantoch MJ, Can J Cardiol 1997

• Teens who are knowledgeable about their CHD are more likely to be confident communicating directly with MD/RN, rather than have their parents do so
  
  Clarizia NA, Can J Cardiol 2009
The CHAPTER 1 Study

- Congenital Heart Adolescents Participating in Transition Evaluation Research

- Aims:
  - To develop and evaluate a clinic-based transition intervention for youth with CHD
  - To measure change in transition “readiness” measured before and after our transition intervention
The CHAPTER 1 Study

- **Congenital Heart Adolescents Participating in Transition Evaluation Research**

- **Aims:**
  - To develop and evaluate a clinic-based transition intervention for youth with CHD
  - To measure change in transition “readiness” measured before and after our transition intervention
The CHAPTER 1 Study: Methods

- Cluster randomized trial
  - Intervention group: Nurse-led 1-on-1 session with teen
  - Usual care group (controls)
- Clusters:
  - Determined by week of attendance in pediatric clinic
- Control group:
  - Unaware of intervention offered to intervention group (different consent form)
The CHAPTER 1 Study: Methods

- Stollery Children’s Hospital
- Inclusion criteria:
  - 15-17 year olds with moderate or complex CHD
- Exclusion criteria:
  - Cognitive delay
  - Heart transplantation
- Enrollment period: January 2011 - May 2012
CHAPTER 1 Intervention Protocol

1. Discussion of “transition” and what that means
2. Create of a MyHealth passport (SickKids Good2Go program)
   - Name of cardiac condition(s)
   - Previous cardiac surgery/catheterizations
   - Name, dose, and rationale for cardiac meds
3. Review diagram of participant’s CHD anatomy
4. Discuss 3 potential late cardiac complications
CHAPTER 1 Intervention Protocol

5. Contact names and location of adult CHD clinic

6. Discuss 3rd person scenarios of risk-taking behaviours

7. Intro to websites

8. Youth-friendly take-home written materials (drugs, STDs, etc.)

9. Text-message/email follow-up within 7 days
CHAPTER 1 Outcome Measures

• Primary:
  • Change in Transition Readiness Assessment Questionnaire (TRAQ) score from baseline to 6 months
  • Two domains:
    - Self-management
    - Self-advocacy

• Secondary:
  • Change in CHD knowledge (“MyHeart” score)
  • Qualitative analysis of text messages/emails
Transition Readiness Assessment Questionnaire (TRAQ)

- 29-items, marked using Likert scale

- Original publication:
  - 192 subjects age 16-26 years, variety of health conditions
  - Scores (range 1-5) increase with age in both domains
  

- Best validated transition tool
  
  Zhang et al. *BMC Pediatrics* 2014
<table>
<thead>
<tr>
<th>Skills for Chronic Condition Self-Management</th>
<th>Not needed for my care</th>
<th>No, I do not know how</th>
<th>No, I do not know how but I want to learn</th>
<th>No, but I am learning to do this</th>
<th>Yes, I have started doing this</th>
<th>Yes, I always do this when I need to</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Do you fill a prescription if you need to?</td>
<td></td>
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</tr>
<tr>
<td>2. Do you know what to do if you are having a bad reaction to your medications?</td>
<td></td>
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</tbody>
</table>
Enrolled 66 participants

58 Analyzed

27 Intervention
(11 F, 16 M)
3 declined the intervention but completed the questionnaires
24 completed the intervention

31 Usual Care
(17 F, 14 M)

8 (12%) Withdrew
3 Usual Care, 5 Intervention
CHAPTER 1: Self-Management

Heart 2014
CHAPTER 1: Knowledge

Heart 2014
MyHeart scale

• Questions with greatest improvement:

1. **Have you had any heart catheterizations?**
   (a) Yes  (b) No  (c) Not Sure
   If YES, how many have you had? What were they for?

2. **How long do you think you should be followed by a cardiologist who specializes in congenital heart disease?**
   (a) when new problems arise  (b) for a few more years
   (c) for the rest of my life  (d) I don’t know

3. **Do you need to take an antibiotic before you see a dentist?**
   (a) Yes  (b) No  (c) Don’t Know
   If YES, why is this antibiotic recommended?
Healthcare transition for youth with heart disease: a clinical trial

Andrew S Mackie,1,2,3 Sunjidatul Islam,3 Joyce Magill-Evans,4 Kathryn N Rankin,2 Cheri Robert,2 Michelle Schuh,1 David Nicholas,5 Isabelle Vonder Muhll,6 Brian W McCrindle,7 Yutaka Yasui,3 Gwen R Rempel8

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Texting teens in transition

- 7 days following intervention session

- Study protocol questions:
  - “Do you have any questions?”
  - “Where is your passport right now?”
  - “Have you shown your passport to anyone?”
Texting teens in transition

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2011-06-15 3:31 PM

I did find out a bit more about tattooing and the risk of endocarditis. Can I email that to you?

Yes please!

2011-06-15 4:12 PM

I just sent you some tattoo information.

One more thing - did you find your phone # to put on your health passport?

Oh i will

2011-06-30 3:51 PM

Excellent. Have you shown it to anyone?

In my wallet

What did they say?

They just were like "so thats why you got a scar"

What about your mom? Did you show it to her?

Yea i did, she said that it was handy
Benefits of texting teens:
✓ Good uptake among study participants
✓ Flexibility for teen and nurse
✓ Fits within adolescent’s social networking-saturated lives
✓ Variety of topics covered
✓ Transcript easily recorded for data purposes

Rempel et al. *JMIR* 2014
Texting Teens in Transition: The Use of Text Messages in Clinical Intervention Research

Gwen R Rempel¹, RN, PhD; Ross T Ballantyne², BScN-Honors, RN; Joyce Magill-Evans³, PhD; David B Nicholas⁴, RSW, PhD; Andrew S Mackie⁵, MD, SM

- Texting themes: RN as source of
  - Information
  - Advice
  - Affirmation
    - e.g. “I was impressed by your knowledge- keep up the good work!”- Nurse

Rempel et al. JMI R 2014
Chapter 1: What we *really* learned...

- Need dedicated nursing time
- Dedicated teaching space within the clinic area
- Interventions on same day as clinic visit
- Parents struggled with being left out
Chapter 1: What we really learned…

- Having a close friend join intervention sessions worked well for some female participants

- Outcome data is hard to get from teens
  - $$ incentive for questionnaire completion
  - Persistence… bug them often

- Health passports need to be smartphone-friendly

- Expect to get texts anytime of the day or night… set boundaries!
CHAPTER 2 Study

- What is the role of a nurse-led 1:1 coaching session with respect to communication skills and self-advocacy?

- Do transition interventions impact adult CHD clinic attendance? Clinical outcomes?

- What is the long-term retention of CHD knowledge among young adults?
CHAPTER 2 Study

• Design: Cluster randomized trial

• Similar to CHAPTER 1, except:
  • 2 intervention sessions with nurse, not 1
  • 2 centers: Stollery Children’s and SickKids, Toronto
  • 120 subjects
CHAPTER 2 Study

• **Primary outcome:**
  • “Excess time” to first adult CHD visit
  • Time interval between final pediatric clinic visit and first adult clinic attendance, minus the recommended time interval between these visits

• Example:
  - Recommended time to first ACHD appt: 12 months
  - Actual interval: 18 months
  - Excess time: 18-12= 6 months
CHAPTER 2 Study

• **Secondary outcomes:**
  - MyHeart score (CHD knowledge)
    - Baseline and 1, 6, 12 and 18 months
  - TRAQ Self-management and Self-advocacy scores
  - Incidence of cardiac re-intervention (surgery or interventional catheterization) at 12 and 24 months
CHAPTER 2 Hypotheses

• **Primary hypothesis:**
  - The *transition intervention* in combination with usual care will result in improved time to 1st adult clinic attendance compared to usual care alone

• **Secondary hypotheses:**
  - The transition intervention will result in improved
    - CHD knowledge
    - Self-management
## Session 1 vs. Session 2

<table>
<thead>
<tr>
<th></th>
<th>Session 1</th>
<th>Session 2</th>
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</thead>
<tbody>
<tr>
<td><strong>Aim</strong></td>
<td>To inform youth about their heart condition</td>
<td>To motivate youth re: self-management</td>
</tr>
<tr>
<td><strong>Role of nurse</strong></td>
<td>Teacher</td>
<td>Coach/Facilitator</td>
</tr>
<tr>
<td><strong>Duration</strong></td>
<td>60-75 minutes</td>
<td>60 minutes</td>
</tr>
<tr>
<td><strong>Content</strong></td>
<td>• Same as CHAPTER 1&lt;br&gt;• Goal setting&lt;br&gt;• Visit to adult clinic</td>
<td>• Review/ discuss videos of “good” vs. “suboptimal” communication&lt;br&gt;• Role-playing, etc.</td>
</tr>
</tbody>
</table>
Videos
Intervention: Session 2

- Held two months after session 1

- Done in-person (hospital) when possible
  - GoToMeeting.com, Skype, or teleconference if subject unable to meet in person

- Led by same study nurse who did session 1
Intervention Fidelity

• Consistency between nurses and between centers
• In-person training session (Gwen Rempel, RN) held in Toronto for Toronto nurses
• Training videos created with standardized patients
  • Session 1
  • Session 2
• Audio recordings of CHAPTER 2 participants
  • Review by team members; Coding of content
  • Regular teleconferences between Edmonton-Toronto
• Field notes completed by RN after every session
A cluster randomized trial of a transition intervention for adolescents with congenital heart disease: rationale and design of the CHAPTER 2 study

Andrew S. Mackie¹,²*, Gwen R. Rempel³, Adrienne H. Kovacs⁴, Miriam Kaufman⁵,⁶, Kathryn N. Rankin¹, Ahlexxi Jelen⁵, Cedric Manlhiot⁵, Samantha J. Anthony⁵, Joyce Magill-Evans⁷, David Nicholas⁸, Renee Sananes⁵, Erwin Oechslin⁴, Dimi Dragieva⁵, Sonila Mustafa⁵, Elina Williams², Michelle Schuh² and Brian W. McCrindle⁵,⁶
Results: Excess Time

Product-Limit Survival Estimates
With Number of Subjects at Risk and 95% Confidence Limits

+ Censored
Logrank p=0.0943
Results: MyHeart Score
Results: TRAQ Self-management
Qualitative Data Analysis

- **Data sources:**
  - nurse logs
  - field notes
  - audio recordings of Session 1 and 2 (n=32)
  - follow-up text message/emails between RN and participant

- Data management using NVivo 10 software

- Content and thematic analysis
Qualitative Results

- 57 participants in intervention group
  - 57/57 did Session 1
  - 54/57 (95%) did Session 2
  - 111 sessions of data for analysis

- Most valuable intervention components, according to participants, were
  - Creation of the MyHealth Passport
  - Goal setting
  - Role-plays
Categories of Teens in Transition

- The independent adolescent: 46%
- The ready adolescent: 26%
- The "follow-up needed" adolescent: 14%
- The "at-risk" adolescent: 9%
- Unclassified: 5%
Categories of Teens in Transition

- The independent adolescent
- The ready adolescent
- The "follow-up needed" adolescent
- The "at-risk" adolescent
- Unclassified

40% required more intervention
1. The independent adolescent (5%)

- Confident and engaged during sessions
- Already knowledgeable about their CHD
- They already had demonstrated self-management skills, including:
  - Scheduling appointments and picking up prescriptions
  - Engaging in active discussions with health-care professionals
2. The ready adolescent (46%)

- Receptive and eager to learn during sessions
- Knowledge about their CHD at enrolment was less developed as were self-management skills
- Required some prompting and coaching during the sessions but were inquisitive and committed to learning
- Appeared to have gained knowledge of their CHD and transition, and practiced self-advocacy skills
3. The “follow-up needed” adolescent (26%)

- Some were receptive to teaching sessions whereas others would lose attention

- During the sessions, they appeared to have minimal knowledge about their CHD or self-management skills

- Affect: reserved, not inquisitive → extensive prompting and encouragement needed from study RN

- Some extra coaching needed
4. The “at-risk” adolescent (14%)

- Difficult to engage during the sessions

- During Session 1, they appeared to have little to no knowledge about their CHD or self-management skills

- Individuals appeared “at-risk” related to:
  - engaging in risky behaviours (e.g. alcohol, smoking)
  - experienced stress reactions during teaching sessions (n=1)
  - strained relationships with parents
Nursing Perspective

Three Levels of Engagement

Highlights
- Study videos
- “Sex, Drugs, and Rock & Roll” conversations
- Role playing
- Goal setting
Nursing Perspective

Challenges

- Technical
- Unpredictability - i.e., participant anxiety
- Rapport in a short time for the shy or disengaged
- Protocol vs. momentous moment

Tricks of the Trade

- Expect the unexpected
- Find comfort in silence
- Spotlight objective observations
Nursing Perspective

Rewards

- Mutual excitement for second session
- No parents to interject
- Teaching them to look around corners
- Giving them a bubble of safety
- Hope for their future

Take Home Message
CHAPTER 3 Study

- Pilot RCT
- 13-14 year olds
- Single nurse-led intervention
- Outcomes:
  - MyHeart score
  - TRANSITION-Q score
- 41 enrolled to date (target 60)
What is “transition” and why does it matter?
  - Loss to follow-up: who, why, and when
Transition interventions
  - CHAPTER Studies: 1, 2 and 3
Knowledge translation
Future directions
Knowledge Translation

- Transition intervention now routine at Stollery Cardiology clinic
  - Ages 16-17

- Led by Jody Gingrich, RN
Knowledge Translation

• “When You’re 18”
Knowledge Translation

• MyHeart scale

Healthcare transition for youth with heart disease: a clinical trial

Andrew S Mackie,¹,²,³ Sunjidatul Islam,³ Joyce Magill-Evans,⁴ Kathryn N Rankin,² Cheri Robert,² Michelle Schuh,¹ David Nicholas,⁵ Isabelle Vonder Muhl,⁶ Brian W McCrindle,⁷ Yutaka Yasui,³ Gwen R Rempel⁸
Future Directions

- Systematic review of transition interventions

- Transition interventions for
  - Teens with acquired heart disease
  - Teens in remote communities
  - Parents

- Re: “Excess time to 1st adult appointment”:
  - Distribution among medical centers?
Future Directions

• RCT of patient navigator service

• Psychometrics of MyHeart score

• Further developing transition interventions at Stollery
  • Family-Centred Care Program
Why is Transition Important?

• JR: 23 year old male with congenital heart disease (CHD) repaired in infancy, comes to an Emergency Room with dizziness and palpitations
  • Doesn’t know the name of his CHD
  • Thinks he’s “cured”
  • Last seen age 17 in pediatric cardiology, told to attend adult clinic in 1 year but moved to another city after high school, didn’t know how to find an adult clinic and felt OK so didn’t bother
Conclusions (1)

• Exponential rise in the number of adult CHD survivors

• At risk of late cardiac complications

• Loss to follow-up is prevalent both in childhood and at the time of transfer

• Loss to follow-up predisposes to need for re-intervention
Conclusions (2)

• Adolescents and parents living with CHD want help with transition

• Adolescents (and young adults) have poor knowledge about their condition and the need for follow-up

• Communication skills with health care providers also lacking in this age group
Conclusions (3)

- It is possible to develop an evidence-base for transition interventions

- A simple nurse-led educational intervention improves medical knowledge and self-management skills (CHAPTERs 1 and 2)

- Ongoing evaluation and refinement of our interventions is essential
Acknowledgements

- Edmonton
  - Kathryn Rankin
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  - Yutaka Yasui
  - Isabelle Vonder Muhll

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  - Brian McCrindle
  - Miriam Kaufman
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