TRANSITION FROM PAEDIATRIC TO ADULT CARE

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Paediatric Endocrinologist
CLINT EASTWOOD
THE GOOD, THE BAD AND THE UGLY
Outline

- Background
- What happens to paediatric patients post-transition?
  - Glycaemic control and complications
  - Clinic attendance
- How well do we prepare for successful transition?
- Can a case management intervention improve outcomes?
- Consumer feedback
- Summary
BACKGROUND

Definition
Introduction
Emerging adults
Definition of Transition

• Purposeful, planned movement of adolescents and young adults with chronic physical and medical conditions from child-centred to adult-oriented health care systems

• PubMed Medical Subject Heading (MESH) search term 2012
  • ‘Transition to Adult Care’

Introduction

• Majority will transition successfully
  • Focus on preventing unsuccessful transition in most vulnerable
  • Facilitate an uninterrupted and supportive process for all

• Clinical research difficult
  • Inherent to the tracking of individuals through multiple healthcare systems and models
  • Challenge of engaging young adults in the research process

The emerging adult

• Timing of transition varies from centre to centre
  • Largely occurs between 18-25 years of age
  • After completion of secondary level education

• This period of life increasingly referred to as ‘emerging adulthood’
  • Characterised by a multitude of life changes, increasing risk behaviours and priorities which focus on exploration of possible life directions

• Ongoing brain development until the mid-twenties
  • Vulnerable to the effects of prolonged hyperglycaemia
  • Leading to subtle neurocognitive dysfunction

Arnett JJ, American Psychologist. 2000;55:469-80
HbA1c and Clinic Attendance: Chicken and Egg?

- HbA1c is not just about insulin doses and food
- Clinic attendance is not just turning up
- Complex psychosocial background
  - Behaviours, beliefs, support systems, mental health, resilience……..
- High HbA1c = potential barrier to attending
  - Issues with working memory and cognition
  - Reluctance to be admonished
- Strategies to emphasise importance from the time of diagnosis
  - Education
  - Supports
  - Follow up of missed appointments
Transition Knowledge Base: What works?

Uncontrolled studies, not prospective, limits generalisability

- Familiarity with adult physician
- Transition within the same hospital
- Information technology
- Transition coordinator
- YADS clinics

Nakla M et al, Pediatrics. 2009
Kipps S et al, Diabetic Medicine. 2002
Vanelli M et al, Diabetes nutrition and metabolism. 2004
Cadario F et al, Clinical Endocrinology. 2009
Gosden C et al, Arch Dis Child. 2010
Wilson SJ et al, Pract Diab Int. 1999

Johnston P et al, Pract Diab Int. 2006
Johnson B et al, Diabetic Medicine. 2014
Holmes-Walker DJ, Diabetic Medicine. 2007
Van Wallegham N et al, Diabetes Care. 2008
WHAT HAPPENS TO PAEDIATRIC PATIENTS POST-TRANSITION?

The Good
The Bad
The Ugly
GLYCEMIC CONTROL AND COMPLICATIONS
Post-transition clinical outcomes from RCH: Glycemic trajectory and Complications

Mean pediatric \( \text{HbA}_1c \):
- \( > 8.2\% \) (Stable High)
- \( \leq 8.2\% \) (Stable Low)

Mean adult \( \text{HbA}_1c \):
- \( > 8.2\% \) (Worsening)
- \( \leq 8.2\% \) (Improving)

Presented at APEG, 2015
<table>
<thead>
<tr>
<th></th>
<th>Overall</th>
<th>Stable low</th>
<th>Improving</th>
<th>Worsening</th>
<th>Stable high</th>
<th>p value</th>
</tr>
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<tbody>
<tr>
<td>N</td>
<td>503</td>
<td>143 (28.4)</td>
<td>82 (16.3)</td>
<td>96 (19.1)</td>
<td>182 (36.2)</td>
<td>-</td>
</tr>
<tr>
<td>Age at transition</td>
<td>18.4 (0.9)</td>
<td>18.5 (0.8)</td>
<td>18.3 (0.8)</td>
<td>18.4 (1.1)</td>
<td>18.4 (1.2)</td>
<td>0.1</td>
</tr>
<tr>
<td>Age at last follow up</td>
<td>27.9 (6.3)</td>
<td>26.4 (5.1)</td>
<td>30.4 (7.7)</td>
<td>27.6 (5.5)</td>
<td>28.4 (6.3)</td>
<td>&lt;0.01</td>
</tr>
<tr>
<td>Duration of DM</td>
<td>18.1 (7.5)</td>
<td>15.5 (6.7)</td>
<td>21.3 (8.6)</td>
<td>17.5 (7.4)</td>
<td>18.9 (7.0)</td>
<td>0.07</td>
</tr>
<tr>
<td>Mean Pediatric HbA1c</td>
<td>8.4 (1.2)</td>
<td>7.4 (0.6)</td>
<td>8.9 (0.9)</td>
<td>7.6 (0.5)</td>
<td>9.3 (0.9)</td>
<td>&lt;0.01</td>
</tr>
<tr>
<td>Mean Adult HbA1c</td>
<td>8.6 (1.6)</td>
<td>7.4 (0.6)</td>
<td>7.6 (0.5)</td>
<td>9.2 (1.0)</td>
<td>9.9 (1.6)</td>
<td>&lt;0.01</td>
</tr>
<tr>
<td>Lifetime mean HbA1c</td>
<td>8.4 (1.1)</td>
<td>7.5 (0.3)</td>
<td>8.3 (0.8)</td>
<td>8.1 (0.6)</td>
<td>9.4 (0.9)</td>
<td>&lt;0.01</td>
</tr>
</tbody>
</table>

Transitioned 1992-2013
Severe complication rates low

<table>
<thead>
<tr>
<th>Complication</th>
<th>n</th>
<th>(%)</th>
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</thead>
<tbody>
<tr>
<td>Renal Failure</td>
<td>8</td>
<td>1.5%</td>
</tr>
<tr>
<td>ESRF</td>
<td>2</td>
<td>0.4%</td>
</tr>
<tr>
<td>Ulceration/Amputation</td>
<td>5</td>
<td>0.9%</td>
</tr>
<tr>
<td>Severe Eye Disease</td>
<td>19</td>
<td>3.7%</td>
</tr>
<tr>
<td>Death</td>
<td>5</td>
<td>0.9%</td>
</tr>
</tbody>
</table>

No difference between the trajectory groups
Severe retinopathy: Is paediatric HbA1c more or less important than adult HbA1c?

- **Paediatric HbA1c**
  - Each 1% rise in mean HbA1c = 2.4 times risk of severe retinopathy
- **Adult HbA1c**
  - No significant increased risk
- **When combined**
  - Paed HbA1c = 3.2 times risk
  - Adult HbA1c = 2.6 times risk
- **Duration of T1DM**
  - Each year = 1.4 risk of severe retinopathy

*White M et al, 2016, In press*
CLINIC ATTENDANCE PRE- AND POST-TRANSITION

Who is most likely to successfully transition?
Attendance rates

- High paediatric attendance
  - Overall = annual attendance at ≥3 paediatric clinics from diagnosis to transition
  - 12 months pre-transition = attendance at ≥ 3 clinics

- Low paediatric attendance
  - Overall = annual attendance at <3 clinics from diagnosis to transition
  - 12 months pre-transition = attendance at <3 clinics

- Adult attendance
  - Same parameters
  - Assessed over the first and second 12 months post-transition

- Disengaged
  - Attendance at zero appointments in first or second 12 months post-transition
Who is most likely to successfully transition?

<table>
<thead>
<tr>
<th></th>
<th>Overall pediatric attendance</th>
<th>12 months pre-transition</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>High Attenders n=315 (63.3%)</td>
<td>Low Attenders n=183 (36.7%)</td>
</tr>
<tr>
<td>Pediatric-adult interval, years</td>
<td>0.6 [0.3, 2.4]</td>
<td>0.4 [0.2, 1.2]</td>
</tr>
<tr>
<td>High Adult attendance</td>
<td>First 12 months post-transition</td>
<td>113 (22.7)</td>
</tr>
<tr>
<td></td>
<td>Second 12 months post-transition</td>
<td>222 (44.6)</td>
</tr>
<tr>
<td>Disengaged</td>
<td>First 12 months post-transition</td>
<td>212 (42.6)</td>
</tr>
<tr>
<td></td>
<td>Second 12 months post-transition</td>
<td>159 (31.9)</td>
</tr>
<tr>
<td>HbA1c Transition</td>
<td>8.4 (1.7)</td>
<td>8.2 (1.5)</td>
</tr>
</tbody>
</table>
HOW WELL DO WE PREPARE FOR SUCCESSFUL TRANSITION?

The Good
The Bad
The Ugly
Transition Letter Frequency

• Audit July 2011-June 2013
  • n=180

• Transition letters sent in 149/180 = 82.8%

• Planned
  • Transition referral letter within 30 days of last RCH visit
  • n= 125/180 = 69.4%

• Unplanned
  • Transition referral letter >30 days after last RCH visit
  • n= 24/180 = 13.3%

• Disengaged/cessation of care
  • No letters/no record of transition discussion
  • n= 31/180 = 17.2%

White M et al, 2012, Diab Manage (Lond)
## Letter Quality: 12 key pieces of information

<table>
<thead>
<tr>
<th>Clinical Detail</th>
<th>Overall</th>
<th>Planned</th>
<th>Unplanned</th>
<th>p value</th>
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<tbody>
<tr>
<td></td>
<td>n=149</td>
<td>n = 125</td>
<td>n = 24</td>
<td></td>
</tr>
<tr>
<td></td>
<td>% (number)</td>
<td>% (number)</td>
<td>% (number)</td>
<td></td>
</tr>
<tr>
<td>Current insulin regimen</td>
<td>98.6 (145)</td>
<td>97.6 (122)</td>
<td>95.8 (23)</td>
<td>0.2</td>
</tr>
<tr>
<td>Complication status</td>
<td>91.2 (134)</td>
<td>90.4 (113)</td>
<td>87.5 (21)</td>
<td>0.5</td>
</tr>
<tr>
<td>Previous HbA$_1c$</td>
<td>85.7 (126)</td>
<td>84 (105)</td>
<td>87.5 (21)</td>
<td>0.8</td>
</tr>
<tr>
<td>Mode of presentation</td>
<td>70.8 (104)</td>
<td>71.2 (89)</td>
<td>62.5 (12)</td>
<td>0.3</td>
</tr>
<tr>
<td>Date of diagnosis</td>
<td>66.7 (98)</td>
<td>66.4 (83)</td>
<td>62.5 (15)</td>
<td>0.6</td>
</tr>
<tr>
<td><strong>GP details</strong></td>
<td>61.9 (91)</td>
<td>60.8 (76)</td>
<td>62.5 (15)</td>
<td>0.9</td>
</tr>
<tr>
<td>Previous insulin regimens</td>
<td>55.8 (82)</td>
<td>56.8 (71)</td>
<td>45.8 (11)</td>
<td>0.3</td>
</tr>
<tr>
<td>Presence/ absence of comorbidities/general medical history</td>
<td>49.7 (73)</td>
<td>47.2 (59)</td>
<td>58.3 (14)</td>
<td>0.4</td>
</tr>
<tr>
<td>Type 1 diabetes antibody status</td>
<td>48.9 (72)</td>
<td>48 (60)</td>
<td>50 (12)</td>
<td>0.9</td>
</tr>
<tr>
<td><strong>Copy of transition letter to youth/family</strong></td>
<td>44.9 (66)</td>
<td>42.4 (53)</td>
<td>54.2 (13)</td>
<td>0.3</td>
</tr>
<tr>
<td>Contact mobile number for youth</td>
<td>8.8 (13)</td>
<td>8.8 (11)</td>
<td>8.3 (2)</td>
<td>0.9</td>
</tr>
<tr>
<td><strong>Overall score</strong></td>
<td>7.9 (2.3)</td>
<td>7.9 (2.3)</td>
<td>7.7 (2.1)</td>
<td>0.6</td>
</tr>
</tbody>
</table>
TRANSITION INTERVENTION: CASE MANAGEMENT

The Good
The Bad
The Ugly
TrACeD: Transition to Adult Care in T1DM

• Multicentre randomised controlled trial, n=120
  • Intervention group, n=60
    • Case management
    • Pre-appointment telephone calls and text messages
    • Rebooking of missed appointments
  • Control group, n=60
    • Usual care
    • No contact with me for the duration of the trial

• Primary Outcome
  • Clinic attendance and disengagement rates in first year post transition

• Secondary outcomes
  • Clinic attendance rates in second year post transition
  • HbA1c in first and second year post-transition
Preliminary Results

- 12 months post-transition (primary outcome)
  - No effect of intervention on clinic attendance, disengagement or HbA1c
  - Overall disengagement low at 8.7%

Preliminary data, 2016
CONSUMER INPUT

The Good
The Bad
The Ugly
Feedback from TrACeD: Why did one fifth of participants change provider at least once?

<table>
<thead>
<tr>
<th>Issues</th>
<th>n=41</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>None</td>
<td>11</td>
<td>26.8</td>
</tr>
<tr>
<td>Different doctors</td>
<td>9</td>
<td>21.9</td>
</tr>
<tr>
<td>Transport</td>
<td>6</td>
<td>14</td>
</tr>
<tr>
<td>Work/Uni commitments</td>
<td>5</td>
<td>12.2</td>
</tr>
<tr>
<td>Unsupported</td>
<td>5</td>
<td>12.2</td>
</tr>
<tr>
<td>Delays at clinic</td>
<td>2</td>
<td>4.9</td>
</tr>
<tr>
<td>Not happy overall</td>
<td>3</td>
<td>7.3</td>
</tr>
</tbody>
</table>
Real Diabetes: Outcomes

- Consumer (patient) satisfaction was increased and key interventions which may potentially improve attendance rates were recommended which continue to the present day;
  - SMS reminders
  - Welcome sheet which is provided with the first appointment notification letter
  - Cancellation of clinics during known events (e.g. examination weeks)
  - Presence of a diabetes nurse educator at each clinic

Colman PG. 2014. Reality Check Transition Project: Final and Evaluation Reports.
SUMMARY
<table>
<thead>
<tr>
<th>The Good</th>
<th>The Bad</th>
<th>The Ugly</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Glycaemic control and complications</strong></td>
<td>Low rates of severe complications</td>
<td>Small number of individuals maintain HbA1c &lt;8.2%</td>
</tr>
<tr>
<td><strong>Clinic attendance rates post-transition</strong></td>
<td>High paediatric attenders likely to be high adult attenders</td>
<td>Frequent prolonged interval between paediatric and adult review</td>
</tr>
<tr>
<td><strong>How well do we prepare for transition?</strong></td>
<td>Template and procedures in place to ensure higher rates and quality of information</td>
<td>Letters not always timely, quality often poor, critical details missing</td>
</tr>
<tr>
<td><strong>Can case management improve post-transition attendance/disengagement?</strong></td>
<td>Lower rates of disengagement year 1 than previously; potentially may increase retention rates at 2 years</td>
<td>No effect in first year HbA1c at transition predicts future HbA1c</td>
</tr>
</tbody>
</table>
Acknowledgements

Supervisors
- Professor Fergus Cameron
- Dr Michele O’Connell
- Professor Peter Colman
- A/Professor Matt Sabin

TrACeD RCT
- RMH
- Sunshine
- Northern Hospital
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- The Alfred
- The Austin
- St Vincent’s
- Monash Health
- Participants

Grant support

Leon Heffer
Knight Wang

A/Prof Susan Donath
Questions?

Advice for Transition Groups

'Cos it's not all a bed of roses.