Transition to adult care

McMaster Children’s Hospital
Developmental Pediatrics Rounds
April 24, 2012
Kathleen Nolan, PGY-4
Julie

• 17 year old girl with:
  – Severe spastic quadriplegic CP, etiology unknown
  – Global developmental delay
  – Seizure disorder with frequent episodes of status epilepticus
  – G-tube fed due to poor weight gain and recurrent aspiration pneumonias
Julie

- Julie has been followed by the same pediatrician since age 6 months
- The family has expressed concerns regarding transfer when she turns 18
  - Who will be her primary care provider?
  - Who will be her neurologist?
  - The adult ED won’t know how to manage her seizures
  - Where will she be admitted if she is sick?
Julie

• “I feel when she turns 18 she’s going to drop into a black hole. I gotta find something out before that black hole happens.”

– Jennifer, Julie’s mother
MIND THE GAP
Objectives

• Medical Expert
  – Define and state the major goals of transition

• Scholar
  – Describe the state of literature today in transition research

• Collaborator
  – Be familiar with available resources to aid in the transition of youth with special health care needs and in their application in a team-based model
Outline

• Transition defined
• Transition from a developmental perspective
• Why is this an issue now?
• Research: what we know and what we don’t
• Recommendations
Transition Defined

• “A multi-faceted, active process that attends to the medical, psychosocial, and educational/vocational needs of adolescents as they move from child to adult-centred care”

Developmental Perspective

• Erickson’s stages of psychosocial development
  – Identity vs Role confusion: Finding out who they are
  – Intimacy vs Isolation: Establishment of stable intimate relationships

Developmental Perspective

• Normal adolescent developmental issues
  – Quest for independence and assertiveness
  – Importance of peer relationships
  – School and work
  – Physical appearance
  – Sexuality

Biological Perspective
Biological Perspective

• Adolescent brain is undergoing myelination and synaptic pruning, particularly in prefrontal cortex

• These changes are important for executive functioning

• Restructuring between regions of prefrontal cortex and limbic system affect interpretation of risk and reward

Why is transition such a big deal now?
Why is this an issue now?

• More youth with chronic conditions are surviving to adolescence and adulthood
  – ~ 15% of youth in North America have a chronic condition
  – US: ~500,000 youth with special health care needs transition to adulthood yearly
  – Estimated that up to 98% of children with a chronic health condition will reach 20 years of age

Why is this an issue now?

- **Cystic Fibrosis**
  - 1970s, average lifespan was 7 years
  - Now, average survival is mid 30s
  - Estimated that children born today with CF may survive to 60 years of age

- **Spina Bifida**
  - 1970s, <30% reached adulthood
  - Now, 60-80% survive to at least 20 years of age

Transition research: What we know and what we don’t

- Transition time is high-risk
- We could be doing a better job
- Youth and family perspectives
- Developmental disabilities
- Health care provider perspectives
- Transition program outcomes
Transition time is high risk
Sickle Cell Disease

- Dallas Newborn Cohort includes 940 subjects with sickle cell disease born 1983 or later
- Deaths occurring 2004-2007 were analyzed
  - Total 7 deaths
  - 6 occurred after transition to adult care
  - Mean time between transfer and death was 1.8 years (0.2-5.3 years)

Kidney transplants

• Rianthavorn et al
  – Although graft survival at 1 year in adolescents is among the best, graft survival at 5-6 years posttransplantation is the least successful in the adolescent recipient
  – 53% admitted non-compliance rate in adolescents compared to 17% in younger children

• Watson studied 20 renal transplant patients who had been transferred to adult care
  – 8 transplants failed within 36 months of transfer, 7 of those were unexpected failures

Type I Diabetes

• Diabetes UK cohort
  – Patients with insulin-dependent diabetes who died before 40 years of age in southeast England
  – 146 deaths, 98 case records available

# Type 1 Diabetes

## Table 1—Descriptive characteristics of the case and control subjects

<table>
<thead>
<tr>
<th>Characteristic</th>
<th>Cases</th>
<th>Control subjects</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>98</td>
<td>137</td>
</tr>
<tr>
<td>n</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Sex</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>53 (54.1)</td>
<td>71 (51.8)</td>
</tr>
<tr>
<td>Female</td>
<td>45 (45.9)</td>
<td>66 (48.2)</td>
</tr>
<tr>
<td>Year of birth</td>
<td></td>
<td></td>
</tr>
<tr>
<td>1940–1949</td>
<td>1 (1.0)</td>
<td>1 (0.7)</td>
</tr>
<tr>
<td>1950–1959</td>
<td>11 (11.2)</td>
<td>11 (8.0)</td>
</tr>
<tr>
<td>1960–1969</td>
<td>61 (62.2)</td>
<td>91 (66.4)</td>
</tr>
<tr>
<td>1970–1977</td>
<td>25 (25.5)</td>
<td>34 (24.8)</td>
</tr>
<tr>
<td>Year of diagnosis of diabetes</td>
<td></td>
<td></td>
</tr>
<tr>
<td>1950–1959</td>
<td>1 (1.0)</td>
<td>1 (0.7)</td>
</tr>
<tr>
<td>1960–1969</td>
<td>3 (3.1)</td>
<td>2 (1.5)</td>
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<tr>
<td>1970–1979</td>
<td>77 (78.6)</td>
<td>109 (79.6)</td>
</tr>
<tr>
<td>1980–1989</td>
<td>16 (16.3)</td>
<td>24 (17.5)</td>
</tr>
<tr>
<td>1990–1993</td>
<td>1 (1.0)</td>
<td>1 (0.7)</td>
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<tr>
<td>Age at diagnosis (years)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Under 5</td>
<td>14 (14.3)</td>
<td>20 (14.6)</td>
</tr>
<tr>
<td>5–9</td>
<td>28 (28.6)</td>
<td>46 (33.6)</td>
</tr>
<tr>
<td>10–14</td>
<td>43 (43.9)</td>
<td>58 (42.3)</td>
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<tr>
<td>15–19</td>
<td>5 (5.1)</td>
<td>4 (2.9)</td>
</tr>
<tr>
<td>20–24</td>
<td>0 (0.0)</td>
<td>7 (5.1)</td>
</tr>
<tr>
<td>25–29</td>
<td>2 (2.0)</td>
<td>2 (1.5)</td>
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<tr>
<td>Age at death (years)</td>
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<td></td>
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<tr>
<td>Under 10</td>
<td>0 (0.0)</td>
<td></td>
</tr>
<tr>
<td>10–19</td>
<td>12 (12.2)</td>
<td></td>
</tr>
<tr>
<td>20–29</td>
<td>53 (54.1)</td>
<td></td>
</tr>
<tr>
<td>30–39</td>
<td>33 (33.6)</td>
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</table>
We could be doing a better job
We are not addressing important transition issues

- National survey of children with special health care needs

**TABLE 3.** Percent Successfully Achieving Components of the Transition Planning Core Outcome

<table>
<thead>
<tr>
<th>% Meeting Core Outcome Components</th>
<th>Doctor Has Talked About Changing Needs in Adulthood (N = 5533)</th>
<th>Child Has Plan for Addressing Changing Needs (N = 2839)</th>
<th>Doctors Discussed Shift to Adult Provider (N = 2871)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Overall percentage</td>
<td>50.0 ± 1.3</td>
<td>59.3 ± 1.7</td>
<td>41.8 ± 1.7</td>
</tr>
<tr>
<td>Race/ethnicity</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Non-Hispanic white</td>
<td>52.1* ± 1.4</td>
<td>58.3 ± 1.8</td>
<td>40.6* ± 1.9</td>
</tr>
<tr>
<td>Non-Hispanic black</td>
<td>49.9* ± 4.6</td>
<td>61.8 ± 5.4</td>
<td>38.1* ± 5.6</td>
</tr>
<tr>
<td>Hispanic</td>
<td>31.6* ± 4.6</td>
<td>63.1 ± 8.8</td>
<td>56.4* ± 7.7</td>
</tr>
<tr>
<td>Non-Hispanic other</td>
<td>45.7* ± 6.8</td>
<td>71.3 ± 5.8</td>
<td>58.8* ± 7.8</td>
</tr>
<tr>
<td>Age, y</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>13–15</td>
<td>49.8 ± 1.6</td>
<td>57.0 ± 2.1</td>
<td>36.3* ± 2.1</td>
</tr>
<tr>
<td>16–17</td>
<td>50.2 ± 2.3</td>
<td>63.1 ± 2.6</td>
<td>51.2* ± 2.8</td>
</tr>
</tbody>
</table>

We are not addressing important transition issues

- 32 patients with CF ≥ 16 years of age recruited from pediatric tertiary care centre

Adolescents with chronic disease have a rocky course

- Survey of 1158 Dutch young adults 18-30 years
  - 650 had a history of childhood cancer, anorectal malformations, Hirschsprung’s disease, esophageal atresia, or end-stage renal disease. 508 controls
  - Achievement of developmental milestones quantified using “Course of Life Questionnaire”, which assesses autonomy development, psychosexual development, social development, antisocial behavior, and substance use and gambling
  - Young adults with chronic disease achieved significantly fewer milestones, or at an older age than their peers, in all course-of-life domains

How youth and families feel about transition
Cystic Fibrosis

- Westwood et al studied 47 patients with CF and their parents regarding their attitudes towards transition to adult care
  - Timing: Most thought transition should occur at 16-18 years
  - Feelings: Of those patients who had not yet transitioned, most felt “unsure” or “worried”. Only 20% expressed positive or neutral emotions.
  - Transition process: 87% thought that it would be helpful to have a transition clinic

Heart Transplant

- Anthony et al conducted a qualitative study of 14 patients post-heart transplant (11.7-17.8 years) and 17 parents regarding their attitudes towards transition. 3 themes were identified:

1. Differences between adolescents and parents
   - Youth primarily expressed apathy regarding transition (12/14), while parents expressed worry and anxiety (14/17)

2. Adult care expectations
   - Both parents and youth expected a busier atmosphere with less individual care
   - Most viewed this aspect as negative

3. Transition program development

- Youth and parents felt strongly about the need for collaboration between pediatric and adult centers

  - “The doctors that you would be seeing in the adult hospital should get together with you when you’re in the kids’ hospital and then kind of get to know them before they actually have to go. That’s one thing that would make it easier. Getting to know the doctors before you actually go.”

Youth with chronic disease

• Rutishauser et al studied 283 adolescents (14-25 years) with chronic conditions who had not yet transitioned to adult care. 318 parents were also surveyed
  – Best age to transfer: 18-19 years (50%)
  – Most important factors for decision of timing of transfer: chronological age (38%). Severity of disease was not an important factor (3.5%)

Youth with chronic disease

• Important barriers for transfer:
  – Feeling at ease with the pediatric specialist (45%), anxiety about not knowing the adult specialist (20%), and lack of information about the adult specialist (18%)

• Setting and location of first meeting with adult specialist:
  – Joint transfer meeting most preferable (48% of adolescents, 67% of parents)

Transition for youth with developmental disabilities
Developmental disabilities

• Research is lacking
• These youth are in need of transition services
  – Taylor et al found that 37% of adolescent patients with ADHD were likely to need transition to adult mental health services

Developmental disabilities

• These youth face many difficulties in transitioning to adult care
  – Singh et al studied youth with ASD
    • Often these youth did not meet referral criteria for adult mental health services so received no mental health services as young adults
    • Lack of transition planning
    • Youth with ASD particularly likely to “fall through the cracks”

How health care providers feel about transition
Adult care providers feel frustrated and under prepared

- Hait et al surveyed 1132 adult gastroenterologists caring for patients with IBD
  - 46% felt competent addressing the developmental aspects of adolescents
  - Most felt that adolescent patients demonstrated deficits in knowledge of their medical history (55%) and medication regimens (69%)
  - 51% reported receiving inadequate information from pediatric health care providers

Adult care providers feel under trained

• Peter et al surveyed 65 US internists via questionnaire regarding their concerns for caring for young adults with childhood-onset conditions

• Main issues identified:
  – “Internists may not have the training in congenital and childhood chronic illnesses to prepare them to manage them beyond childhood”
  – “Internists often lack training in adolescent medicine, adolescent development, and adolescent behavior”

Adult care providers feel uncomfortable

- Patel and O’Hare surveyed 220 US residents in internal medicine or pediatric programs
- Pediatric residents were significantly more comfortable treating all childhood-onset chronic illnesses except for asthma

Adult care providers feel uncomfortable

Transition Program Outcomes
Transition Program Outcomes

• Evidence is sparse
• Generally, families and youth report greater satisfaction with the transition process if there is an organized transition program in place
• There is little evidence thus far that an organized transition program improves medical outcome, and there is no evidence regarding which type of transition program is best
Families and youth like organized transition programs

• McDonagh et al studied youth with JIA and their parents prior to and following implementation of a coordinated transition program
  – Compared with prior to program implementation, significant improvements were reported for adolescent and parent’s satisfaction scores

• Evans et al studied youth with multiple disabilities prior to and following participation in “Youth En Route” transition program
  – 78% of youth were mostly to very satisfied with the program

Families and youth like organized transition programs

• Kipps et al retrospectively studied 229 young adults with DM 1 who had transitioned to adult care in 4 districts in the UK
  – District A: pediatric clinic → adult clinic
  – District B: pediatric clinic → adult clinic (different hospital)
  – District C: pediatric clinic → adolescent clinic (same hospital) patients introduced to adult physician prior to transfer
  – District D: pediatric clinic → adolescent clinic (run jointly by pediatric and adult physicians) → adult clinic

Table 4 Patient satisfaction with transfer on interview, by district

<table>
<thead>
<tr>
<th>District</th>
<th>A (n = 30), %</th>
<th>B (n = 25), %</th>
<th>C (n = 25), %</th>
<th>D (n = 26), %</th>
<th>Total (n = 106), %</th>
</tr>
</thead>
<tbody>
<tr>
<td>Satisfied</td>
<td>47</td>
<td>56</td>
<td>60</td>
<td>65</td>
<td>57</td>
</tr>
<tr>
<td>Not satisfied</td>
<td>47</td>
<td>12</td>
<td>4</td>
<td>65</td>
<td>20</td>
</tr>
<tr>
<td>Indifferent</td>
<td>6</td>
<td>32</td>
<td>36</td>
<td>23</td>
<td>24</td>
</tr>
</tbody>
</table>

Overall $\chi^2 P < 0.001$.

*More subjects in districts C and D were satisfied with transfer than in districts A and B ($P = 0.014$, of those who expressed an opinion).
†More subjects in district A expressed dissatisfaction with transfer than in districts B, C and D ($P < 0.0001$).

Improvements in health-related quality of life

- McDonagh et al found significant improvement in health related quality of life scores at 6 and 12 months following implementation of a transition program (HRQL:Juvenile Arthritis Quality of Life Questionnaire)
  - Improvements also noted in adolescent and parent knowledge about their disease

Improvements in follow-up

- Kipps et al found improved clinic attendance rates 2 years post-transfer in youth with DM 1 who went through an organized transition program.

![Bar chart showing clinic attendance rates](chart.png)

*Figure 2* Regular clinic attendance rates (at least 6 monthly) at 1 (■) and 2 years post-transfer (□), by district.

Improvements in youth-reported measures

- Evans et al found significant improvements in youth-reported measures following completion of the “Youth En Route” program
  - Significant improvement in areas of self-determination, including autonomy, self-regulation, and self-realization
  - Significant improvement in areas of personal control
  - Significant increases in youth-reported volunteer/work activities and community leisure activities

Improvement in medical outcome

• Compared to no formal transition process, does an organized transition team lead to:
  – Improved HbA1C in youth with DM1?
  – Improved rejection rates in youth post-transplant?
  – Decreased hospitalization rates in youth with CF?
  – Improved disease activity index scores for children with rheumatologic disease?
Should I stop here?
Recommendations for a successful transition
Transition Recommendations

- Based on CPS, AAP, and Society for Adolescent Medicine position papers and review papers by experts in transitional care

Transition Recommendations

1. Youth with special health care needs should have an identified health care provider who attends to the unique challenges of adolescence and transition
2. Early preparation for transition is essential
3. Development of a portable, accessible, medical summary to facilitate smooth collaboration between health care providers
4. Development of an up-to-date detailed written transition plan in collaboration with patients and families no later than age 14
Transition Recommendations

5. A flexible policy on timing of transfer
6. Adults, including those with childhood-acquired chronic conditions, should receive adult oriented primary health care in adult health care settings
7. Transition should include an education program for patients and parents that addresses medical, psychosocial, and educational/vocational aspect of care as well as an approach which fosters personal and medical independence
Transition Recommendations

8. Health care providers should continue to provide appropriate primary and preventive care to youth with chronic conditions.

9. Core competencies required by health care providers to render developmentally appropriate health care should be identified and these skills must be well-taught and integrated into certification requirements.
Where should I start?

• Start talking to your patients about transition early
• Remember the HEADS interview
• Advocacy!
  – Let health care administrators know about the importance of transition
  – Funding
  – Research
  – Formal reviews
Challenges

- Youth with intellectual disabilities
- Youth with multiple, complex medical problems
- Non-compliant youth
- Youth who will be moving to attend school
- Youth with a significantly shortened life expectancy
- Long wait-times in adult care
- …
Back to Julie

- Julie is now 19 years old
- She continues to be followed by her pediatric care providers
- She continues to be seen at the pediatric ED
- Together with her family, the pediatric team continues to work towards transition to adult care
Thank you

Questions?