Lost in Transition: Adolescence 2 Adulthood

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Pediatric Nephrology
“As a disabled child I was an infant. As an adolescent I was a child. In my adult years, I would finally pass through adolescence. Prolonged infancy encouraged dependency. This made the acceptance of personal responsibility difficult. As an adult aged patient I felt cast into a foreign sea. My boat had oars, but I did not know how to use them.”

Margaret Stineman, MD
Objectives

• To identify the challenges faced by youth living with chronic kidney disease
• To describe the concepts of the developmentally-appropriate care and transition planning
• Identify opportunities for better transition care and barriers that need to be overcome for improved transition care
• To describe the tools used in the clinical setting to support youth and their families through the process of transition from pediatric to adult health care settings
Transfer vs. Transition

• **Transfer** is an event in the **transition** process the timing of which depends on many factors other than chronological age, e.g. maturity, disease activity, independence, availability of adult specialty service.
Transition

• “Transition is a process which occurs throughout pediatric care that educates and empowers youth and their families to become active participants in their own care. It is not just the transfer of care to the adult system.”

Rosen D. J Adolesc Health 1995;17:10-16
Transition Goals

- Maximize lifelong functioning and potential
- Developmentally appropriate
- Ensure uninterrupted health care services as the individual moves from adolescence to adulthood
Adolescence

• Concern over body image
  – May affect compliance with medications (e.g. Prednisone, CyA)
Adolescence

• Risk taking
  – Less long-term, future oriented thinking

• Sense of invincibility
Adolescence

- Peer pressure
  - Don’t want to look or feel different from peers
- Health is often not a main priority
Challenges in Pediatrics

• Congenital malformations and inherited disorders
• Attached to patient/families since childhood
• Need lifelong interdisciplinary care
  – Nephrology, urology, neurology, GI and others familiar with “pediatric” conditions
• Complex social situations
• Summarizing years of care
Challenges in Adult Medicine

- Limited resources for multiple needs patients
- Psychosocial development delay
- Patient’s reliance on parents and pediatric interdisciplinary team vs. autonomy
Graft survival rates

• What age group has the highest risk of graft loss at 5 years post-transplant?
  - <1 year olds
  - 1-10 year olds
  - 11-17 year olds
  - 18-34 year olds
  - 35-49 year olds
  - 50-64 year olds
Graft survival rates: 1995 - 2004

OPTN Annual Report
Creatinine before and after transfer in 20 patients

7 unexpected graft losses

Watson AR Pediatr Nephrol 2000
Outcomes of Patients Transferred from BCCH to Various Adults Centres in BC
Study Cohort

• Transferred period:
  – January 1 2000 and December 31 2006

• Outcomes of interest:
  – Survival Time
  – CKD patients: Time to Dialysis or Transplantation
  – Dialysis patients: Time to Transplantation
  – Transplant patients: Time to Graft Loss (defined as requiring dialysis or re-transplantation)

• Outcomes follow-up period:
  – Date of Transferred to August 31 2007
# Baseline Data

<table>
<thead>
<tr>
<th></th>
<th>Overall</th>
<th>CKD</th>
<th>Dialysis</th>
<th>Tx</th>
</tr>
</thead>
<tbody>
<tr>
<td>N</td>
<td>66</td>
<td>23</td>
<td>8</td>
<td>35</td>
</tr>
<tr>
<td>Age (in years)</td>
<td>19.3±1.3</td>
<td>19.1±1.0</td>
<td>19.5±1.2</td>
<td>19.4±1.5</td>
</tr>
<tr>
<td>Male</td>
<td>39 (59%)</td>
<td>14 (61%)</td>
<td>4 (50%)</td>
<td>21 (60%)</td>
</tr>
<tr>
<td>Transferred to</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>IHA</td>
<td>8 (12%)</td>
<td>6 (26%)</td>
<td>0</td>
<td>2 (6%)</td>
</tr>
<tr>
<td>FHA</td>
<td>9 (14%)</td>
<td>5 (22%)</td>
<td>2 (25%)</td>
<td>2 (6%)</td>
</tr>
<tr>
<td>VCHA/PHSA</td>
<td>33 (50%)</td>
<td>10 (43%)</td>
<td>5 (63%)</td>
<td>18 (51%)</td>
</tr>
<tr>
<td>VIHA</td>
<td>4 (6%)</td>
<td>2 (9%)</td>
<td>0</td>
<td>2 (6%)</td>
</tr>
<tr>
<td>NHA</td>
<td>3 (5%)</td>
<td>0</td>
<td>1 (12%)</td>
<td>2 (6%)</td>
</tr>
<tr>
<td>Unknown</td>
<td>9 (13%)</td>
<td>0</td>
<td>0</td>
<td>9 (25%)</td>
</tr>
</tbody>
</table>
# Outcomes Data

<table>
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### Observed Outcomes:

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<th>Overall</th>
<th>CKD</th>
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</tr>
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<tbody>
<tr>
<td>Deaths</td>
<td>4 (6%)</td>
<td>1 (4%)</td>
<td>0</td>
<td>3 (9%)</td>
</tr>
<tr>
<td>Starting Dialysis*</td>
<td>16 (28%)</td>
<td>10† (43%)</td>
<td>0</td>
<td>6 (17%)</td>
</tr>
<tr>
<td>Transplantation</td>
<td>9 (14%)</td>
<td>6† (67%)</td>
<td>3 (38%)</td>
<td>0</td>
</tr>
</tbody>
</table>

* Applicable to only CKD and Transplant patients:

- N for Overall Column = 23 (CKD) + 35 (TX) = 58
- % Starting Dialysis for Overall Column = 16/58 x 100% = 28%
- † There were 4 patients who started dialysis and then followed by transplantation.
Kaplan-Meier Estimated Survival (Overall Cohort)

Survival at 12 months: 97% [95% CI: 93% - 100%]

Note: Results above remain similar when censoring at transplantation
Kaplan-Meier Estimated Time to Dialysis or Transplantation (CKD Patients)

Free of Dialysis or Transplant at 12 months: 83% [95% CI: 68% - 99%]
Kaplan-Meier Estimated Time to Transplantation (Dialysis Patients)

Free of Transplant at 12 months: 75% [95% CI: 50% - 100%]
Kaplan-Meier Estimated Time to Dialysis or Transplantation (Transplant Patients)

Free of Dialysis or Transplant at 12 months: 85% [95% CI: 74% - 98%]

Probability of Event-Free

# Pts at Risk:

Free of Dialysis or Transplant at 12 months: 85% [95% CI: 74% - 98%]
Kaplan-Meier Estimated Time to Dialysis or Transplantation (Transplant Patients)

Free of Dialysis or Transplant at 12 months: 85% [95% CI: 74% - 98%]

Probability of Event-Free

# Pts at Risk:

0 1 2 3 4 5 6 7 8 9 10 11 12 13 14 15 16 17 18 19 20 21 22 23 24 25 26 27 28 29 30 31 32 33 34 35 36 37 38 39 40 41 42 43 44 45 46 47 48 49 50 51 52 53 54 55 56 57 58 59 60 61 62 63 64 65 66 67 68 69 70 71 72 73 74 75 76 77 78 79 80 81 82 83 84 85 86 87 88 89 90 91 92 93 94 95 96

Months from Discharge From BCCH
Clinical: Transition Framework

<table>
<thead>
<tr>
<th>Early Transition</th>
<th>Middle Transition</th>
<th>Late Transition</th>
</tr>
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<tr>
<td>The youth and the family are introduced to the transition process and the youth begins to participate in his/her care</td>
<td>The youth and family gain understanding of the transition process and the youth practices skills, gathers information and sets goals to participate in his/her own care</td>
<td>The youth and family prepare to leave the pediatric setting with confidence and the youth uses independent health care behaviors and consumer skills into adult system</td>
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Years 10 ---------18
Grade 5 -----------12

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**Years 10 -----------18**  
**Grade 5 -----------12**

- Depends on …  
  - Severity & exacerbation of condition  
  - Physical and cognitive abilities  
  - Psychological and emotional stability  
  - Family and social support

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Clinical: Transition Framework

<table>
<thead>
<tr>
<th>Stage</th>
<th>Age Range</th>
<th>Grade Range</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>EARLY ADOLESCENCE</strong></td>
<td>Ages 10-12</td>
<td>Grade 5-7</td>
</tr>
<tr>
<td><strong>MIDDLE ADOLESCENCE</strong></td>
<td>Ages 13-15</td>
<td>Grades 8-10</td>
</tr>
<tr>
<td><strong>LATE ADOLESCENCE</strong></td>
<td>Ages 16-18</td>
<td>Grades 11-Graduation</td>
</tr>
</tbody>
</table>

- Self-Advocacy
- Independent Health Care Behaviors
- Sexual Health
- Educational, Vocational, financial Planning
- Social Supports
- Health & Lifestyle

Developed in collaboration with the Building-a-bridge project for youth with endocrine conditions at BCCH.
Clinical Pathway for Adolescent Transition Care

Youth Between 10 - 18 yrs of age

Initiate Clinical pathway on health care record. Review process with youth & family

**EARLY TRANSITION**
Youth/family identify concerns. Pathway section completed

- Chronic health condition requiring ongoing adult care
- Minimum of 2 visits or 1 yr. from diagnosis

Initiate transition tools as chosen. Youth Planer, Family care book, Workshop

Early Transition needs met?

- Yes
  - MIDDLE TRANSITION
  - Youth/family identify concerns. Pathway section completed
  - Attend Transition Clinic/workshop
  - Complete transition process evaluation (youth, family, staff)

- No
  - Refer to appropriate resources. Make formal referral

Youth Health Consultation Service
Genetic Counseling
GF Strong Adolescent & Youth Adult Program
Sexual Health Resource Center
Mental Health

**MIDDLE TRANSITION**
Youth/family identify concerns. Pathway section completed

Middle Transition needs met?

- Yes
  - LATE TRANSITION
  - Youth/family identify concerns. Pathway section completed
  - Transition Pathway Completed?

- No
  - Refer to appropriate resources. Make formal referral

**LATE TRANSITION**
Youth/family identify concerns. Pathway section completed

- Yes
  - Complete Transition summary & transfer youth to adult care

- No
  - Refer to appropriate resources. Make formal referral

Communicate needs (focus to Adult Care Providers)
BCCH Renal Transition Clinic

• Introduced in January 2007
• Vision:
  – Family-centered
  – Continuous
  – Comprehensive
  – Compassionate
  – Developmentally appropriate
Transition Team

• Pediatric nephrologist and renal nurse
• Adolescent medicine physician and nurse
• Renal pharmacist
• Renal dietician
• Social worker
• Administrative clerk
Readiness for Transfer

- Identifies primary care provider
- Youth knows and understands
  - Their renal disease & need for renal replacement/transplant
  - Impact on reproductive health and potential
    - Pregnancy, teratogenicity, fertility
    - Genetic risk of disease recurrence
    - Health care standards: cancer screening, immunizations, etc.
Readiness for Transfer

• Knowledge of consequences of non-adherence

• Youth’s ability for disease self-management
  – Medications names, purposes, doses, refills
  – Making appointments, knowing where to go
  – Seeking medical assistance when needed
  – Knowledge of renal diet
Components of Transition/Transfer

- Interdisciplinary teams
- Patient is medically stable
- Issues of non-adherence addressed
- Individual assessment of readiness
- Insurance coverage
- Transfer discharge summary
- Communication with the adult team
Transition Summary

Name ___________________________ DOB ___________ PHN ___________________________

Address _________________________________________________________________

Phone ___________________________ Home ___________________________ Work ___________________________ Cell ___________________________

Emergency Contact: ___________________________ Relationship: ___________________________ Phone: ___________________________

Family physician: ___________________________

Allergies (meds & food): ___________________________

Height: _______ Weight: _______

BP at last visit: _______

Diagnosis

1. ___________________________

2. ___________________________

3. ___________________________

<table>
<thead>
<tr>
<th>Current Medications</th>
<th>Current Medications</th>
</tr>
</thead>
<tbody>
<tr>
<td>1.</td>
<td>5.</td>
</tr>
<tr>
<td>2.</td>
<td>6.</td>
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<tr>
<td>3.</td>
<td>7.</td>
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<tr>
<td>4.</td>
<td>8.</td>
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</tbody>
</table>

Medic alert bracelet Yes [ ] No [ ]

Dietary/Nutritional Needs: ___________________________

<table>
<thead>
<tr>
<th>Most recent investigations</th>
<th>Date</th>
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<tbody>
<tr>
<td>1.</td>
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<td>2.</td>
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<tr>
<td>4.</td>
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<tr>
<td>5.</td>
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</table>

Past Hospitalizations (including surgeries)

<table>
<thead>
<tr>
<th>Date</th>
<th>Hospital Name</th>
<th>Reason</th>
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Psychosocial assessment

Home (Family, Housing, Transportation):

Education & Work:

Activities:

Drugs:

Sex: ___________________________

Summary:

Signature Nephrologist: ___________________________ Date Completed: ___________________________

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Pediatric Nephrology, BCCH
604-875-2272

Gee Wigle, Transplant Nurse Coordinator
604-875-3604

Tanya Studhin, Social work
604-875-2345X7393

Paula Woo & Nonnie Pollard, Dietitians
604-875-2348X7157

BC CHILDREN'S HOSPITAL
An agency of the Provincial Health Services Authority
Thank you

- Adeera Levin, MD
  BCPRA
- Douglas Matsell, MD
- Marg Turik, RN
- Gee Wigle, RN
- Jorge Pinzon, MD
- Sara Miles, RN
- Kathleen Collin, PharmD
- Tanya Strubin, MSW
- Paula Woo, RD
- Nonnie Polderman, RD
- Jennifer Leechik, RN
- Lorraine Nicado, RN
- Theresa Ferraro
- Lee Er, BCPRA
"Son, I think you're old enough now to know about the birds and the fleas."