A Developing Psychosocial Program for Chronic Kidney Insufficiency & Kidney Transplantation

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European Working Group on Psychosocial Aspects of Children with Chronic Renal Failure

Dun Laoghaire, Ireland

Camillia Clark, Ph.D.
Anne MacNeill, MSW
Nephrology Clinic
Alberta Children’s Hospital,
Calgary, Canada
Introduction

• Some Canadian Statistics
  – Pediatric Nephrology centers in Canada
• Nephrology Clinic at Alberta Children’s Hospital in Calgary, Alberta
  – Area served
  – Comparison to Ireland/U.K.
  – Brief history
  – Clinic population descriptors
• Psychosocial Program
Kidney Transplants,¹ Pediatric and Adult Recipients. Canada 1982-2000 (Age-adjusted Rate Per Million Population)


¹ Includes cadaveric and living organ kidney transplants.
Pediatric Kidney Transplant Rate and the Canadian Population Under 18 Years of Age, 1982-2000

Pediatric Kidney Transplant Recipients by Age Group, Canada, 1982-2000 (Number)

Background Information

- Alberta Children’s Hospital - large pediatric outpatient and inpatient hospital serving city of Calgary, surrounding area including southeastern British Columbia and southwestern Saskatchewan
- Teaching hospital affiliated with the University of Calgary Medical Center
- Hospital philosophy:
  - Family Centered Care
  - Multidisciplinary teams
- Children birth - 18 years of age
History of Nephrology Clinic

- Established 10 years ago (July/August 1994)
- Dr. Julian Midgley joined by Dr. Donckerwolcke in 1995
- After he left, Dr. Andrew Wade joined Dr. Midgley in 1999 and since then 2 more Nephrologists have joined the clinic
- In 2004 - 4 Nephrologists, 4 clinical nurses, pharmacist, dietician, social worker, psychologist
- First transplant October 1995
Clinic Population

- 30 transplants performed at ACH
- Average age at transplant, 10 years;
  - age range, 2.5 to 18.4 years
- 7 children currently on dialysis; 6 PD, 1 HD
- 61 children with chronic kidney insufficiency
- Many other children followed for various kidney related difficulties
## ACH Clinic Population by Age Group

<table>
<thead>
<tr>
<th>Transplants</th>
<th>Infants &lt;5 years</th>
<th>School Age 5-12 years</th>
<th>Teenagers 13-18 years</th>
</tr>
</thead>
<tbody>
<tr>
<td>LRD (14)</td>
<td>0</td>
<td>6</td>
<td>8</td>
</tr>
<tr>
<td>CRD (11)</td>
<td>0</td>
<td>6</td>
<td>5</td>
</tr>
<tr>
<td>HD (1)</td>
<td>0</td>
<td>0</td>
<td>1</td>
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</tbody>
</table>

<table>
<thead>
<tr>
<th>Dialysis</th>
<th>Infants &lt;5 years</th>
<th>School Age 5-12 years</th>
<th>Teenagers 13-18 years</th>
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</thead>
<tbody>
<tr>
<td>PD (6)</td>
<td>1</td>
<td>1</td>
<td>4</td>
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<tr>
<td>Severe &lt;30*</td>
<td>1</td>
<td>2</td>
<td>3</td>
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</table>

<table>
<thead>
<tr>
<th>CKI</th>
<th>Infants &lt;5 years</th>
<th>School Age 5-12 years</th>
<th>Teenagers 13-18 years</th>
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<tbody>
<tr>
<td>Moderate &gt;30&lt;60*</td>
<td>3</td>
<td>7</td>
<td>4</td>
</tr>
<tr>
<td>Mild &gt;60&lt;90*</td>
<td>3</td>
<td>19</td>
<td>19</td>
</tr>
</tbody>
</table>

**Totals** 8 41 44

*ml/min/1.73m²
Primary Focus of Psychosocial Team

• Issues:
  – Adjustment
  – Preparation
  – Medication noncompliance
  – Transition
  – Economic and financial
  – Academic and school

• Intervention Methods:
  – Individual and family therapy, marital therapy, counseling for parenting issues, psychological assessment
  – Support/group therapy
Key Elements of Psychosocial Involvement

• Multidisciplinary team approach for all transplanted children and children with chronic kidney insufficiency
• Have established specialty clinics for transplant and CKI patients
• Early introduction of the psychosocial team
• Philosophy of early intervention
• Regular clinic reviews for all children/adolescents
• Continuity of psychosocial care - outpatient clinic and inpatient
Specific Psychosocial Activities

• Kidney Kamp
• Family Picnic
• Support Group
Kidney Kamp

• 9th Annual - 40 children/adolescents
• Gives children/adolescents living with chronic kidney disease an opportunity to participate in normal activities in a safe and healthy environment
• Held at a residential outdoor camp in the foothills of the Canadian Rockies (Camp Horizon)
• Provides a natural support system
• Long-lasting friendships developed
• Provides self-confidence and independence
• Allows respite
Annual Family Picnic

• Third Annual
• Provides an opportunity for entire families to enjoy a special day together
• Held at a historical park and village within Calgary’s city limits (Heritage Park)
• Over 200 people attended last year
• Allows families to find support and friendship with other families living with kidney disease
• Gives siblings an opportunity to participate and share in activities
Support groups

- Two new support groups within the Nephrology Clinic:
  - Parent Support Group
  - Child/Adolescent Support Group
- Need identified from parents and patients
- Held once a month at the Hospital
- Lead by team members of the Nephrology Clinic
- Connected by telephone video conferencing to outlying areas for participation
Parent Support Group

• Special key note presentations by various team members
• Support environment established to:
  – Bring parents together
  – Identify concerns and issues in a non-medical setting
  – Educate parents about new resources and programs
  – Parents to overcome challenges and demands
  – Provides education and support for new families
  – Creates a safe place for parents to talk about their hopes, sadness, grief, disappointments, frustrations
Child/Adolescent Support Group

- Builds peer support and friendships
- Helps children/adolescents identify issues through activities such as art, games, crafts, renal jeopardy
- Allows issues related to school adjustment, hospital experiences, medication compliance to be addressed in a non-medical environment
- Opportunities for developing ongoing support outside the hospital setting
- A natural place for friendships to begin
The Game of Renal Jeopardy at the Child/Adolescent Support Group
Transition Planning

• A structured transition planning approach is being developed based on the work from the Children’s & Women’s Health Centre of British Columbia
• Focus on preparation starts in early adolescence – 10 years of age – enough time to develop skills and knowledge
• Ongoing process; developmental considerations
• Partnership between youth, family and health care providers
Future Directions

- Expand psychosocial program, especially support groups
- Development of a mentorship program
- Connect other outlying remote areas to support groups through telephone video conferencing
- Develop more programs for prevention of high risk behaviors
  - Early intervention!
- Develop research to assess therapeutic outcomes