Transitioning from Pediatric to Adult Care in Sickle Cell Disease and Hemophilia

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Transfer from Pediatric to Adult Care

- The Teen Health Gap
- Challenges
  - Patient
  - Health Care Providers
  - Resources
- Our Approach
  - Hemophilia
  - Sickle Cell Disease
  - Transition Strategies
Culture of Care: Pediatric Provider

- Family-centered
- Developmentally oriented (school and life progress)
- Nurturing, high level psychosocial support
- Interdisciplinary
- Involve parent direction and consent
- Flexible
Culture of Care: Adult Provider

- Individual-based care (not family)
- Disease focused (not developmentally)
- Cognitive approach (rather than nurturing)
- Multidisciplinary (rather than interdisciplinary)
- Requires patient to be autonomous and function independently

From ‘Coming of Age with Diabetes – Patients’ views of a clinic for under 25 year olds’
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Definition:

*Transitional care* is a process that attends to the medical, psychological, social and educational-vocational needs of adolescents as they move from child-oriented lifestyles and systems.
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Challenges: The patient

• Feeling “dumped”, “abandoned”, tossed into the adult milieu

• Leave behind their medical team

• A knowledge gap in the receiving team

• The emergency room/ admissions to an adult hospital
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Challenges: The Health Care Provider

Comfort zone:
- Pediatricians: < 16 years of age
- Adult physicians: “older patients”

- Time constraints: Adolescents want to talk about more than just their disease or symptoms
- Knowledge
- Supports in the hospital setting
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Challenges: Resources

- Adult hospitals are not as “warm and fuzzy”
- Resources/support staff are very different from a pediatric centre
  - Social work
  - Physiotherapy
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Adult Primary Care Provider Response: Comfortable or Very Comfortable Treating Young Adults with Following Conditions

- Internist
- non-Continued Care FP
- Continued Care FP

Young Adults in General

Sickle Cell

Rhode Island Dept of Health 2007
Hemophilia and Sickle cell at CHEO:

- Both comprehensive care programs are housed in 6 West
- Patients are followed throughout their lives at CHEO
- Adult investigations, emergency room visits and admissions are at one of the two adult hospitals: the Ottawa Hospital General campus or Civic campus
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Hemophilia Program: Staff

- Two hemophilia nurses on site at CHEO
- Dedicated physiotherapist at CHEO
- Part-time data keeper (CHARMS)
- Social Work
- Administrative Support
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Hemophilia Program: Services

- Clinics every six months with nursing, hematologist and physiotherapy at CHEO
- Coagulation concentrates supplied by CHEO Blood Bank
- Ambulatory “emergency” care at CHEO
- Fortunately parallel services provided at Ottawa General Campus with dedicated hemophilia nurse – less administrative/data support
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Sickle Cell Anemia Program

- Large pediatric program at the CHEO
- Until recently, no adult program in the city of Ottawa
- Dedicated nurse with backup at CHEO
- Dedicated nurse desperately needed at OGH – currently applying for funding
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Transition strategies:

• Hemophilia Transition evening
  – April 16, 2009
  – Hemophilia nurses/physicians/physiotherapists from both CHEO and OGH
  – Recently transitioned patients presented
  – Unfortunately poor turnout
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Transition strategies:

• Quarterly transitions meetings
  – Reality is more like annual meeting
• Adequate transfer of documentation
  “summary letter” + recent tests
• OGH nurse comes to CHEO to meet particularly difficult patients
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Lessons:

• It’s difficult for patients and families

• The biggest hardship for patients is the emergency room facilities

• Most quickly value their autonomy

• Resources