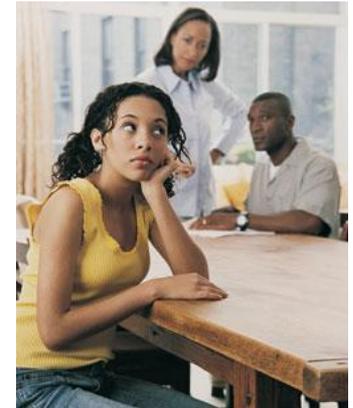# BRIDGING THE GAP

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

Transfer from Pediatric to Adult Care

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.

Transfer from Pediatric to Adult Care

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

Transfer from Pediatric to Adult Care

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
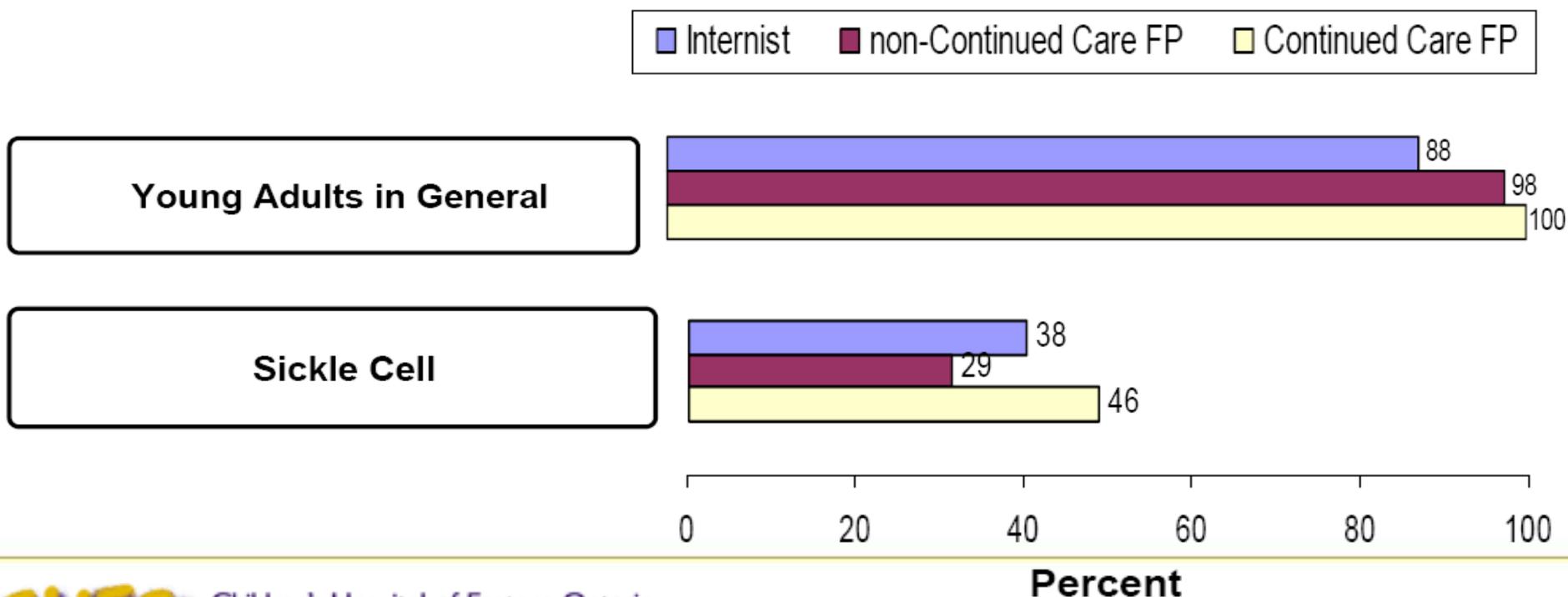
- Supports in the hospital setting

Transfer from Pediatric to Adult Care

Challenges: Resources

- Adult hospitals are not as "warm and fuzzy"
- Resources/support staff are very different from a pediatric centre
  - Social work
  - Physiotherapy

Transfer from Pediatric to Adult Care

Adult Primary Care Provider Response: Comfortable or Very Comfortable Treating Young Adults with Following Conditions

Rhode Island Dept of Health 2007

Transfer from Pediatric to Adult Care

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

Transfer from Pediatric to Adult Care

Hemophilia Program: Staff

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

Transfer from Pediatric to Adult Care

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

Transfer from Pediatric to Adult Care

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

Transfer from Pediatric to Adult Care

Transition strategies:

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

Transfer from Pediatric to Adult Care

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

Transfer from Pediatric to Adult Care

Lessons:

- It's difficult for patients and families

- The biggest hardship for patients is the emergency room facilities

- Most quickly value their autonomy

- Resources

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