The Transition of Young Adults with Sickle Cell Disease from Pediatric to Adult Care Setting

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Objectives

1. Discuss the challenges of children and adolescents with chronic illness transitioning to an adult setting.
2. Review of sickle cell disease and disease specific factors that should be taken into consideration when transitioning from pediatric to adult settings.
3. Review evidence based practice and directions for research for transitioning and use of palliative care principles for pediatric to adult settings for young adults with sickle cell disease.
4. Discuss several transition programs for children with sickle cell disease and challenges encountered.

Transition - movement, passage, or change from one position, state, stage, subject, concept, etc., to another; change: the transition from adolescence to adulthood.

Transition is a process that should evolve over time......

should not happen overnight
90% of Children with Special Needs are surviving into adulthood

These young adults will require transition to adult settings

Schwartz, Tuchman, Hobbie & Ginsberg (2011)

Challenges of children and adolescents with chronic illness transitioning to an adult setting

Cultural Differences in Care from Healthcare Professionals

- **Pediatrics**
  - Typical patient’s healthy only a minority is chronically or terminally ill
  - Patient seen as fragile, vulnerable, dependent
  - Family-centered care parents always involved
  - Shared decision making and education focuses on parents rather than on patients
  - Informal, relaxed communication style, empathic but also more paternalistic
  - Holistic care attention to physical, mental and learning issues, social functioning
  - Interdisciplinary team approach

- **Adults**
  - Typical patient has complex, chronic and often progressive condition
  - Patient seen as co-responsible, self-reliant
  - Individual-based care
  - Empowerment of patient by means of sharing information and expectations of self-reliance
  - Formal and direct communication style, more distant and "business-like"
  - Disease-oriented care strong focus on treatment complications and adherence
  - Specialist orientation, less team work and care co-ordination

Van Staa, Jedeloo, Meeteren & Latour (2011)
Advantages and disadvantages of pediatric and adult care, as perceived by young adults and their parents

Von Staa, Jedeloo, Meeteren & Latour (2011)

Transition to adult care: experiences and expectations of adolescents with a chronic illness


SMART Model
Social-ecological model of AYA (adolescents and young adults readiness for transition)
SMART Model

![Diagram of the SMART Model]

Ethical Considerations in Transition

- Preserving, promoting and ensuring dignity and respect for patients
- Fostering and supporting the trusting relationships
- Recognizing graduated capacity
- Promoting autonomy and self-management
- Duties of beneficence and non-maleficence
- Truth-telling
- Duty to provide developmentally appropriate care
- Duty of pediatric providers to advocate for transitioning patients in the adult system

Insurance Issues

- Should be a group discussion at multiple times during the transition process.
  - Social worker take the lead with making sure adolescent understands process and walk them through filling out forms
- Review when no longer covered on parent insurance
Access to Care

- What are the options?
- Who are the providers?
  - What is the philosophy of the clinic/provider?
- Is the clinic/provider covered by insurance?
- Transportation to appointments
- Do appointment times work with school/work hours?

Got Transition: 6 Core Elements of Health Care Transition

1. Transition Policy
2. Transition Youth Registry
3. Transition Preparation
4. Transition Planning
5. Transition and Transfer of Care
6. Transition Completion

http://www.gottransition.org/6-core-elements-table

Example of Transition Checklist
Sickle Cell Disease

Inheritance Pattern of Parents with Heterozygous Hemoglobin Variant S. A normal hemoglobin gene; S abnormal hemoglobin gene

http://www.ncbi.nlm.nih.gov/pmc/articles/PMC2932707/figure/F1/

Chronic Pain Issues

• Avascular necrosis of joints
• Skin ulcers
• Osteomyelitis
• Chronic pain syndromes including neuropathic pain

Psychosocial Factors with SCD

• More problems with adjustment
• Internalize their thoughts and feelings
• Thoughts of limitations on prospects of future careers and achievements
• Body image
• Interpersonal relationships with family members

Howard, Woodland, Musumadi, Martell & Inusa (2010)
Neurocognitive Needs

High risk of neuropsychological impairments
- Chronic anemia
- Hypoxemia
- Cerebrovascular ischemia and stroke

• Results of study
  - Increased risk of problem with executive function
  - Speed of procession
  - Graphomotor function
  - Academic achievement
  - Parent-reported anxious/depressed symptoms

Wills, Nelson, Hennessy, Nwaneri, Miskowiec, McDonough, & Moquist (2010)

Career Planning

• College or Technical School
  - Is an IEP or 504 plan needed
• Jobs
  - Accommodation to be considered

Family Support with Transition

• Helping families to foster independence of the child
• Help with moving from family centered care principles to self decision making
• Poor modeling may affect process of transition
Barriers to Transition in SCD

- Health care disparities
- Adolescent and family don’t want to transition
- Access to adult facility
  - Use ED vs. PCP

Transition from pediatric to adult care in sickle cell disease: Establishing evidence-based practice and directions for research

Bio-ecological systems theory

- Environmental factors
  - Microsystem
  - Mesosystem
  - Exosystem
  - Macrosystem
Transtheoretical stages of change mode

- Precontemplation
- Contemplation
- Stable

Conceptual Model of the Tasks of Transition

There are many overlapping tasks during the transition

Potential Tool for Annual Assessment

- Health care skills checklist
- Educational and vocation skills checklist
- Health benefits checklist
- Social support checklist
- Independent living checklist
- Feeling, stress, and strength checklist
- Sickle cell stress
- Sickle cell disease self-efficacy
Use of Palliative Care Principles for Transition to Adult Setting

Roles of Providers

- **Physician**
  - Provide ongoing education
  - Provide new provider PMH and timeline of patient history

- **Nurse**
  - Provide ongoing education
  - Increase understanding of condition and implications
  - Reinforce to plan
  - Support family with not cradling them

- **Social Worker**
  - Support transition
  - Education on independence with medical needs

- **Psychologist**
  - Identification of barriers and solutions to keeping well
  - Support with transition to college or university
  - Stress management
  - Pain management
  - Sleep difficulties
  - Development of a positive identity
  - Confidence in communication about condition with peers or teachers
  - Communication within the family about management of condition
  - Neuropsychological assessment

Transition Program at NCH

- Discussion of transition starts age 14yo
  - Teach about SCD and how to advocate for themselves

- Transition patients 1-2 times per year at or around age of 21 years old.
  - Patient informed of date and welcomed to participate in transition day to meet support person at OSU with Sickle Cell team from NCH.
  - Tour of OSU

- Appointment date for first visit set up by NCH team to occur after Transition Day.
In closing……

• Transition is never easy from adolescent to young adult care
• Adolescents with chronic illnesses benefit from a dedicated transition process that occurs over time
• Family functioning should be taken into considering with working on transition process
• The transition process requires a dedicated team
• Remember Transition is Never Easy

References


• Tuchman, LK.; Slap, GB.; Britto, MT. “Transition to adult care: experiences and expectations of adolescents with a chronic illness.” Child: Care, Health and Development, v. 34 issue 5, 2008, p. 557-63.