

November 6, 2018

Transitioning Patients with Sickle Cell Disease from Pedi to Adult Care

Philippa Sprinz, MD, MSc

Hasbro Children's Hospital, Providence, RI



Transition

(Many of the following slides with thanks to Joseph Telfair, presented at the first NEPSCC Seminar, Boston 2009)

“Transition of young adults with sickle cell disease (SCD) from pediatric to adult medical care is an important priority, given medical advances that have transformed SCD into a lifelong chronic condition, rather than a disease of childhood.”*

- In last 10 years there has been recognition of the need to address ‘Transition’ in SCD
- Important: *Transition* versus *Transfer*
- Some ‘big names’ in this research:
 - Treadwell, Telfair, Eckman, Lanzkron, Strause, Sobota, Hassell, Haywood, Anie

*Treadwell et al 2011, Am J Hematol

Definition

- Transition is a multifaceted, active process that attends to the medical, psychosocial, and educational/vocational needs of adolescents, as they move from the child - focused to the adult - focused health - care system. Health transition facilitates transition in other areas as well (e.g., work, community, and the school).
- Transition proceeds at different rates for different individuals and families (and programs).

- Quinn, Rogers, McCavit, and Buchanan (2010) found that the incidence of death and mortality changed over the duration of recent (since 1990) cohort
 - Sepsis is no longer the leading cause of death, and all the recent deaths in the cohort occurred in patients 18 years and older — most, shortly after transition to adult care.

Transition is a process over time

- Transition = process over time, not a single event: it has a beginning, middle and end
- Beginning = when a decision is made to prepare for transition
- Middle = the efforts made to prepare for and implement transfer (“transition readiness”)
- End = both the process of transferring to the ‘adult world’ and successfully establishing care with adult providers
- = Both medical and life transition
- Could be considered as the process of helping an adolescent move from a focus on pediatric life skills to adult life skills.

Challenges for the youth are not unique to SCD

- All adolescents/young adults need to learn the systems in the adult world to succeed with the degree of independence our society puts on them.
- Individuals with chronic diseases may need more help and support than their healthy counterparts.
- Medical/health issues will inevitably complicate the steps necessary for the individual to be functional and feel comfortable in the adult world.
- The medical illnesses may cause social, behavioural and emotional difficulties that impair the smooth transition into adulthood.

Treadwell et al 2011, Am J Hematol

Research in Transition in SCD

- Telfair et al (J Adolesc Health 1994) found that the two most pressing concerns for those (patients) involved in the process of transitioning with SCD, were
 - i. payment for medical care
 - ii. how they would be treated in the adult world
- For the parents the primary concerns were
 - i. how would the patient manage with self care
 - ii. how would the patient cope in the adult health care system

Successful transition requires:

- Clear, thoughtful, and informed attention to social and cultural realities of client, caregiver, and provider.
- At a minimum, take a comprehensive approach that is more than one or two hand-off visits to adult providers, and this program must be built into the overall care plan for the young person that begins when he or she is a young adolescent.

But what to do...

- “Social and cultural realities of client” – how do you learn these, if the only significant encounters (time-wise) with the client s when the client is in hospital in a voe or other complication of SCD?
- By teenage years – when not sick many of our patients do not keep OP visits.
- How to help those who had mild disease in their younger years but go on to have more severe in their older years – not good understanding of SCD?
- Need to start process of educating everyone (client, parents, providers, family support, pcp etc.) while client still young enough to understand concepts and needs.

Thank you!