POSITION STATEMENT

Transition of Patients with Sickle Cell Disease from Pediatric to Adult Health Care

AUTHORS

Rosalind Bryant, PhD PNP-BC

Jerlym S. Porter, PhD MPH

Amy Sobota, MD MPH

REVIEWERS

Lisa Bashore, PhD RN CPNP CPON®

Jane S. Hankins, MD MS

Kathryn Hassell, MD

Duyen Ngo, MD

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SUMMARY

With advances in medical care, the majority of children with sickle cell disease (SCD) survive to adulthood. Patients, families, and providers now face the need for this growing population to move from pediatric- to adult-focused care. To facilitate a successful transfer to adult health care and prepare young adults for greater independence, it is recommended that all pediatric patients with SCD receive transition preparation.

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Association Position

As the professional voice of pediatric hematology/oncology healthcare practice, the Association of Pediatric Hematology/Oncology Nurses (APHON) and the American Society of Pediatric Hematology Oncology (ASPHO) recommend that the discussion of transition begins early and be presented as part of the natural process of becoming an adult; that patients, providers, and families are all involved in creating a transition plan and assessing transition preparedness annually; and that the transfer of care involves direct communication between the pediatric team and the accepting adult provider.

Background and Significance

Sickle cell disease (SCD) is a group of genetic blood disorders that leads to significant health complications throughout life and affects approximately 90,000 Americans (Brousseau, Owens, Mosso, Panepinto, & Steiner 2010; Hassell, 2010). Two thousand children are born with SCD in the United States each year (National Heart, Lung and Blood Institute, 2002). Due to recent advances in medical treatment, including universal newborn screening, prophylactic penicillin, targeted vaccinations, hydroxyurea, transcranial doppler, and ongoing parental and patient education, more than 93% of children with SCD now survive to adulthood (Quinn, Rogers, McCavit, & Buchanan, 2010). This creates a need for transitional preparation to facilitate pediatric SCD patients' movement into adult health care.

Transition is defined as a "purposeful, planned" process with a goal of providing continuity of care and preparing young adults for greater independence (Blum et al., 1993). This process typically includes the transfer of care from a pediatric-oriented to an adult-oriented healthcare system. However, transition encompasses more than simply a change of provider and is a life process that should occur regardless of the healthcare setting.

Many patients experience difficulty during this time of transition, with evidence showing an increased rate of emergency visits, rehospitalizations, and morbidity and early mortality for SCD patients in late adolescence and early adulthood (Brousseau, et al., 2010; Hemker, Brousseau, Yan, Hoffmann, & Panepinto, 2011; Quinn et al., 2010). Recent data also highlight an increase in mortality rate during adulthood when compared with patients 19 years and younger (Hamideh & Alvarez, 2013). Patients with SCD face an additional burden of neurocognitive impairments from disease-specific complications such as stroke, silent infarct, and chronic anemia (Schatz, Finke, Kellett, & Kramer., 2002; Wang et al., 2001).

Pretransition process measures, such as a written transition plan, have been identified as important components of quality care for patients with SCD (Wang, Kavanagh, Little, Holliman, & Sprinz, 2011). In response to this data, transition programs are beginning to grow within pediatric SCD clinics around the country (Sobota, Neufeld, Sprinz, & Heeney, 2011).

Problem Statement and Introduction

The goal of transition is to "maximize lifelong functioning and potential through the provision of high quality, developmentally appropriate healthcare services that continue uninterrupted as the individual moves from adolescence to adulthood" (American Academy of Pediatrics [AAP], American Academy of Family Physicians [AAFP], & American College of Physicians-American Society of Internal Medicine [ACP-ASIM], 2002). By definition, transition is a multifaceted, vibrant process initiated with a child- and parent-focused orientation and ending with adult-focused health orientation (DeBaun & Telfair, 2012). With the risk of life-threatening SCD complications, there is a need for all centers caring for such patients to have a transition program or policy to facilitate continued medical care. Despite recognizing the importance of transition as a continuum of health care for adolescents and young adults with SCD, a paucity of established, effective strategies exists (DeBaun & Telfair, 2012). With a limited number of local providers with expertise in SCD, many patients are transferred to a general internist for their adult care (Lebensburger, Bemrich-Stolz, & Howard, 2012; Sobota et al., 2011).

The Center for Health Care Transition Improvement proposes using six core elements of transition as a framework to guide best practices (Got Transition™/Center for Health Care Transition Improvement, 2014). These elements include developing a healthcare transition policy, identifying transitioning youth in a transition registry, assessing and tracking transition readiness, addressing healthcare transition needs with the youth and family, ensuring direct communication between pediatric and adult healthcare providers during the transfer of care, and making contact with the youth 3 months after transfer to ensure a successful completion.

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Recommendations

It is the position of APHON and ASPHO that SCD patients must receive transition preparation to facilitate a successful transition to adult health care. The following represent ideal steps in the transition and eventual transfer of young adults with SCD:

Transition Planning

- Formal discussion about transition and the policy of the practice or institution should begin at age 12 years (or when developmentally ready) and include both the parent and child.
- All patients should have a written transition plan by age 14 years (AAP, AAFP, & ACP-ASIM, 2002). This plan should be developed together with the patient and family and updated annually.
  - Use of either a generic or disease-specific transition readiness assessment can guide patient-specific pretransition preparation and determine the appropriate time for transition (see www.gottransition.org for examples).
  - Patients should have periodic neuropsychological evaluations to identify deficits that may impact their disease management skills and academic or vocational transition planning (Wills et al., 2010).
- Professional organizations such as APHON and ASPHO, which represent providers caring for these adolescent and young adult patients, should advocate for better reimbursement for transition planning and services.

The Transition Team

- The transition team should include physicians, nurse practitioners or physician assistants, nurses, psychologists, and social workers from both the pediatric and adult care settings (Jordan, Swerdlow, & Coates, 2013).
- Pediatric providers should understand and incorporate the perspective of the SCD patient, parent or caregiver, and providers by
  - allowing the patient and caregivers to express feelings (e.g., sadness in leaving pediatric providers, fears about transitioning to a new provider or environment) and concerns regarding transitioning to adult healthcare
  - including family members or caregivers in the transition plan so they may provide additional support for young adults during and after transfer
  - providing additional support for young adults during and after the transfer of care.

Transition Preparation

- Transition preparation should be addressed annually.
  - Specific areas to be addressed include medical topics (SCD complications, disease inheritance) as well as educational and vocational topics.
  - An SCD-specific transition curriculum can be found at: http://nepscc.org/sickle-cell-medical-guide-pediatric-to-adult.pdf (Hankins & the WISCH Transition Affinity Group, 2013).
  - Pediatric providers should directly address insurance issues and any changes in insurance coverage due to age.
- Nursing staff can facilitate transitions by assessing preparedness, resources, relationships, and responsibility as part of individual transfer plans (Fegran, Hall, Uhrenfeldt, Aagaard, & Ludvigsen, 2014).
- Providers caring for patients with SCD can normalize the transition process by helping families see transfer to an adult provider as the next logical step in becoming an adult (Betz, 2013; DeBaun & Telfair, 2012; Lebensburger, et al., 2012).
- Begin an "adult" model of care in the teenage years by having providers see patients alone for part of the visit starting at age 13 years and having patients make their own appointments and calls for medication refills by age 18 years.
- When possible, have patients meet their adult healthcare provider before transfer because this may facilitate posttransfer access to care (Bloom et al., 2012; Hankins et al., 2012).

Transfer of Care

- Partner with primary care; consider staggering transfers so that patients do not leave both primary care and specialty care at the same time.
- Identify accepting adult providers in your area who have, or are willing to develop, expertise in SCD.
- Transfer ideally should occur when patients and families agree that the patient is ready to take on an adult role in his or her care.

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  - If the hospital has a set age for transfer of care, develop a policy for exceptions for patients with cognitive delay or other special needs.
  - Avoid abruptly transferring patients early unless there is a true medical need.
- Communicate directly with the adult provider; send a written medical summary that includes a medical history, an individualized pain management plan, and baseline labs.
  - Encourage family or caregivers and the patient to contribute to the medical plan.
  - Develop practice agreements between pediatric and adult care clinics to facilitate a seamless transition to adult health care (Bryant, Young, Cesario, & Binder, 2011).

Transfer Completion

- Transfer is not complete until the patient has been seen at least once in the adult provider's office. This should happen within 3 months of leaving pediatric care. Consider following patients for an additional 3 months to ensure they are well established in adult care.
- Pediatric and adult care teams should continue to evaluate and adjust their transition process. This evaluation should include the perspective of patients, families, and all involved providers.

Conclusion

All adolescent and young adult patients with SCD should receive transition preparation to help them move successfully from pediatric- to adult-focused health care and achieve greater independence whether they remain in pediatric care or transfer to an adult healthcare setting. Healthcare education prior to, during, and after transfer may reduce morbidity and the high rate of mortality from disease complications.

Resources

Transitioning from Pediatric to Adult Medical Care: A Resource Guide: for information regarding handouts contact Wendy L. Ward PhD, Associate Professor, Arkansas Children's Hospital, UAMS College of Medicine, Department of Pediatrics, 1 Children's Way, Slot 512-21, 501-364-1021, © Byerley and Ward, 2011.

http://www.gottransition.org/providers-best-practices

http://www.gottransition.org/UploadedFiles/Files/Algorithm.pdf

http://www.nepscc.org/NewFiles/Transitionguidebook2012.pdf

http://hctransitions.ichp.ufl.edu/

http://www.nichq.org/stories/SickleCellTransitionCurriculum.pdf

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8735 W. Higgins Road, Suite 300
Chicago, IL 60631
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