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# From Cradle to Commencement: Transitioning Pediatric Sickle Cell Disease Patients to Adult Providers

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## Abstract

Children with sickle cell disease (SCD) are surviving past childhood and well into adulthood. Concerns are raised as to who is going to care for these children as they reach adulthood. We have developed a 2-part transition program. We have transitioned 20 of our 18- to 27-year-old patients to adult providers recognizing that early preparation is essential. At the newborn's initial visit or transfer from another clinic the transition program is explained to the family. At age 13 years, all our patients are given a "Preparation for Transition" binder. This binder is reviewed in detail with the patient and parent on a regular basis. At 18 years of age, coordinating with the milestone of graduating from high school and depending on developmental age, the transition is completed. The goal is a continuum of care in the transition process.

## Keywords

sickle cell disease, pediatric, transition

Children born with sickle cell disease (SCD) are surviving past childhood and well into adulthood because of medical advances that include early detection by newborn screening, referral to a comprehensive SCD center, penicillin prophylaxis, education, and improved management to prevent and minimize the complications associated with this chronic disease.

SCD is the most common genetic disorder in the African American population (Wojciechowski, Hurtig, & Dorn, 2002). In 1973, the life expectancy of children with SCD was 14 years; 30 years later it has increased to 50 years (Claster & Vichinsky, 2003). A growing population, now 1 in 500 African-American newborns have the disease, which leads to concerns of who is to care for these children as they enter adulthood. In Texas alone in 2008, The Newborn Screening Program, Hemoglobinopathy Statistics indicated 411 948 live births and total number of hemoglobin traits as 26 899. Of that number, 5093 infants demonstrated sickle cell trait and 150 infants demonstrated SCD (Texas Department of State Health Service, 2009).

All pediatric SCD health team members strive to provide optimal health care for children with the expectation of them achieving long productive lives and moving on to the care of adult providers (Reiss & Gibson, 2002). Transitioning to an adult provider is an involved process that includes finding a provider, informing the patients and

families, preparing them for the transition, role playing, individual teaching sessions, self-advocacy skill training, telephone triage, liaison, consulting, and consoling. "The optimal goal of transition is to provide health care that is uninterrupted, coordinated, developmentally appropriate, psychosocially sound and comprehensive." (Blum et al., 1993).

## Background

The Children's Regional Sickle Cell Program, part of CHRISTUS Santa Rosa Children's Hospital (CSRCH) and the University of Texas Health Science Center in San Antonio (UTHSCSA), is a comprehensive program providing services to children and adolescents with SCD and their families. In January 2006, an analysis revealed a large number of young adults receiving care, with ages ranging from 18 to 27 years. The CSRCH Emergency Department (ED) admission policies terminate at the age of 16 years. Historically, SCD patients have had special privileges

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with the ED if the hematologist/oncologist informed the ED that a patient exceeding the age limit was coming in for assessment. In that case, the patient would likely be seen in the Pediatric ED (if patient flow and volume permitted) and not sent to Adult ED. If further care was needed, the patient would be admitted to the Pediatric Hematology/Oncology floor.

However, numerous factors needed to be addressed, including having adult and pediatric patients cared for in a pediatric facility with no plans for an adolescent/young adult (AYA) unit and pediatric providers unfamiliarity when providing care to AYAs. In addition, behavioral issues with this population were accelerating and included behaving in an inappropriate manner, parents and patients becoming verbally abusive to staff, leaving against medical advice, and choosing not to communicate with staff when needing to assess level of pain and opioid pain relief. Hospital staff expressed frustration and concern with what appeared to be a number of patients seeking hospitalization and opioid analgesic relief for environmental, psychosocial, and home difficulties. Possible secondary gains from hospitalizations included legal and school problems, as well as, stress from parents and family demands (Reiss & Gibson, 2002). These factors and behaviors were being observed from all levels of hospital staff, including the housekeeping, dietary, and child life departments, as well as services within the hospital to include surgery, radiology, emergency services, and subspecialty clinics.

These factors, combined with a review of the literature concerning the needs of adults with childhood onset chronic illnesses, resulted in the development of a comprehensive plan for transitioning these patients into the adult community. The following describes the process of transitioning the existing young adults with SCD to the adult community and the comprehensive transitioning plan underway to prepare all current patients with SCD and their families for transition from diagnosis forward.

## **Program Development**

In October 2006, the first queries were sent to the community to assess what services were available and who would be willing to accept patients with SCD. At that time, the issue of transition was addressed with all our patients older than the age of 18 years. They were informed that a plan was being developed to transition their care to an adult hematologist. The focus would be to start preparing for this transition by taking an active role in their disease management, communicating with the health team, and becoming more responsible for their health and future needs. At each clinic visit, the signs and symptoms of SCD, a review of their individual health history,

medications, allergies, as well as self-advocacy and communication skills were reviewed and developed with the patient and family.

In February 2007, the First Annual Sickle Cell Research and Educational Symposium—"Transition From Pediatric to Adult Care" organized by Dr Lanetta Bronte, Director, Sickle Cell Services, Memorial Healthcare Systems was held in Hollywood, Florida. This provided a wealth of information, an opportunity for networking, and the motivation to proceed with this project.

In March 2007, 4 community adult providers were contacted by phone and letter to query their interest in participating in our transition program. After that initial contact, a brief written transitioning plan was provided to the 3 providers who responded favorably to the inquiries.

In June 2007, a meeting was held with pediatric and one of the adult physicians and support staff. The transitioning process and concerns were discussed. One idea generated was to bring all potential patients to a "meet and greet" with all willing providers. In July 2007, 2 out of the 4 adult providers confirmed they were willing to take on our SCD patients and the first transition occurred.

With an organized, preplanned transition program, we sought to prevent an emergency "transfer of care" to the adult provider because of inappropriate adult behavior, for example: pregnancy or incarceration. The goal was to transition at the age of 18 years or coinciding with graduating from high school with an appropriate level of maturity. In reality, the age of transition of our patients averaged at 21 years. One 21-year-old patient was "transferred" despite multiple discussions and attempts to encourage the patient and mother to participate in the transition program. This patient was only seen when in crisis and on his way to the ED. Interestingly, the adult provider has communicated that this patient has become a "model" patient. The 18 patients who initially participated in the transition program were between the ages of 18 and 27 years.

Prior to the initial meeting with the adult provider, specific patient information and contact information was given to the adult providers with a detailed transition documentation form to assist in sorting through the documents. A contact person was designated and a release of information was signed. Prior to the last appointment in the pediatric sickle cell center, the patient was called and reminded of the purpose of the last appointment. At the last appointment at the pediatric clinic, the differences between pediatric and adult providers and what to expect were reviewed. One of the most important points was how communication may differ. For example, the adult providers will address questions to the patient not the parent and there may be some personal questions that pediatric providers may not typically ask. Most of the patients

were honest enough to indicate they were apprehensive about the transition but ready to make that milestone. It appeared that the parents acknowledged more anxiety about the transfer of care than did the patient.

At the last clinic visit there was a celebration of transitioning. At this celebration, the pediatric staff, patient, and family had refreshments, and shared stories and memories, and the patient received a small gift.

Prior to the first visit to an adult provider, a letter was sent out to the patient, by certified mail, which included the name, address, phone number, and contact person for the adult provider. A map from their home address to the adult provider's address was included. A follow-up phone call was made to acknowledge receipt of the information and to answer any questions prior to the first meeting with the adult provider. The sickle cell nurse was available to accompany the patient to their first appointment with the adult physician, if desired.

If the pediatric sickle cell nurse attended the first appointment with the adult provider, the patient chose whether to have the nurse go in or wait outside the examination room. A week after the first appointment a follow-up call was made to review with the patient how they felt about the visit and to discuss concerns they may have experienced. With each transition, something new was learned and the process was adapted to incorporate that experience. Once transitioned, it became the patient's responsibility to manage their care with their provider with the understanding that the pediatric team is available to discuss concerns but that their medical care was provided elsewhere.

As the number of transitions progressed, we experienced successes and failures. Three patients failed to show up for their first appointment with the adult provider while the nurse was waiting for them at the adult provider's office. This occurred despite numerous reminders from our center and adult provider, as well as, certified letters with the appointment information. In follow-up contact, 2 of the 3 patients indicated that they had no excuses for their absence and the third has left the area and has not been located. It was then up to these patients to make their own appointment with the adult provider.

One out-of-town college student returned to school in the fall and called wanting to be seen, as she was out of medication and was having symptoms of a vasoocclusive crisis. During the telephone conversation with the patient and subsequent calls from her parent, they both acknowledged receipt of 2 certified letters and several voice-mail telephone messages regarding the transition process. This was a difficult situation for both the pediatric center and the patient. She was provided the phone number and the contact person with the adult provider and strong recommendations that she call as soon as possible. Of the other

2 college students, one did not return to the city and the other was lost to follow-up.

In general, pediatric health care providers are not generally enthusiastic with transitioning their patients as they are concerned with the quality of care that these long-standing patients will receive. We have initiated several attempts to bring together the adult providers and the pediatric center teams to review any issues or concerns that have been experienced since the beginning of the transition process. The adult providers have busy schedules and these meetings have not occurred.

Of the total patients initially transferred, 4 were on our erythrocytapheresis program, which presented a unique set of issues. These patients were informed that all medical care would be given by the adult provider but they continued to be seen in our clinic on a regular basis for erythrocytapheresis averaging every 4 to 8 weeks. CSRCH hospital policy dictates that a physician must complete a physical examination on every patient who is receiving a blood transfusion and write erythrocytapheresis orders. We coordinated the adult provider appointments with the erythrocytapheresis clinic appointments. Unfortunately if the adult providers' appointments were missed or changed, the patients quickly fell back into pediatric mode resulting in multiple "no-shows" with the adult provider office. This resulted in miscommunication between the centers, which hindered the growth of the relationship between the patient and adult provider. This became another reminder to emphasize the goals of transition with the patient.

One has to consider the uniqueness of each individual, namely, their differences, capabilities, education, socioeconomic status, health problems, coping strategies, and maturation level. One major lesson that has been learned is that you cannot change anyone's behavior if they do not see their behavior as a problem (i.e., incarceration, not finishing high school, no job potential, pregnancy, or not having health insurance). Some do not recognize that it is not in their best interest to obtain their health care at the local ED on an as-needed basis.

The second phase of the transition program has been the development and implementation of a comprehensive plan for transition from the entry of the patient into the pediatric health care system. Each new patient is informed at the first appointment that it is a pediatric center and we will care for the patient up until the age of majority (18 years); this applies to transferred patients or patients identified by newborn screening. Our goal is for each patient to transition to an adult provider being knowledgeable, actively involved in their health care and secure in their ability to manage their disease. Each new patient and family is given a binder, including patient information regarding sickle cell disease and treatment, a thermometer, how to give medications, who to call when a problem is

identified or the child is ill, immunization schedules, nutrition information, a wallet medical information card, and Web site references.

One part of the program involves developing medication index cards for patients as young as 1 year. Parents help personalize the cards, which include the names of all medications and doses with stickers and crayons. It is stressed to the patient that this is their medication card and it is as unique as they are. At clinic visits, the medication index cards are reviewed with the patient and the family and a new card is made. One medication card is sent home with the patient with a refrigerator magnet and this becomes an easy means of tracking pain medications used by noting it on the back of the card. The family is instructed to bring the card back to their next appointment. We use inventive techniques to pique the curiosity of the child and family to become interested in their care. Examples include homemade hemoglobin cookies (red cell vs sickle cell), finger puzzles, individual body pain scale, arts and crafts, songs, and microscopic viewing of sickle cells. Additional education information is shared through our newsletter "The Sickle Cell Rapper" that is sent out to our patients quarterly and is available on the State of Texas Newborn Screening Web site ([www.dshs.state.tx.us](http://www.dshs.state.tx.us).) Our goal is to have active participation of our patients from an early age in the hopes that they become active partners with the pediatric team in their health care.

At 13 years of age, each child is given a preparation for transition binder. A thorough explanation of the binder and project goals is given to the parent and the child. The binder includes: skill checklists for home, school, community, future, health care, leisure; tracking sheets for phone calls and appointments: when to call and report a problem, contact numbers, pain management plans; and a journal, educational CD ROMs, and Web site addresses. Additional handouts are added as needed.

At 14 to 16 years of age "Coaching Through the Emergency Department," which is an ongoing project, is offered. The goal is that it will assist the patient to develop the skills necessary to communicate and advocate for themselves from triage through to the discharge from ED. It also demonstrates to the parents that their child is learning new skills to help them take more responsibility for their disease. The drawback of this project is that this is only available on the days that the sickle cell nurse is in the hospital.

## Conclusions

As a team, we are reinforcing to our patients and families that SCD is only part of them, not their entire identity. Regularly in our center we stress the positive aspects about life's struggles acknowledging that is it hard and it is sometimes not fair. During the development of this

preparation program, one area that required tactfulness was the area of career/vocation as it involved talking about the hopes and dreams of the patient. It is truly a delicate situation to assist the patient to strive for their dreams with consideration of the realities of having a debilitating chronic illness that is unpredictable.

We have attempted to bring our teenagers together for peer support groups without success. That is one area that we plan to refocus our efforts on and discuss the many issues that emerge during the teenage years. We also hope to bring together the adult providers, our transitioned patients, and our current patient and families to discuss the concerns of the patients preparing to transition and to draw on the experiences of those that have transitioned.

Our main goal is that children being cared for in our sickle cell center will be knowledgeable about their disease and actively participate in all aspects of their health care from cradle to commencement. It is our hope that through our collective efforts of our team that these patients will be much better prepared for a long successful future, living well with sickle cell disease.

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## Declaration of Conflicting Interests

The author declared no potential conflicts of interest with respect to the authorship and/or publication of this article.

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**Bio**

**Donna M. Doulton** has been privileged to work in Pediatric Hematology/Oncology for over 24 years. Graduated from The School of Nursing at John Abbott College, Ste. Anne de Bellevue, Quebec, Canada, in 1985 followed with a Baccalaurate of Science in Nursing from University of Ottawa, Ottawa,

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