Multidisciplinary Approach to Sickle Cell Disease in the Outpatient Setting

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SJCRH Hematology

- Only pediatric hematology center in the region
- Provides medical care and research from birth to 18 years of age
- January 2000 to September 2006—over 12,000 sickle cell clinic visits occurred
772 pediatric patients with sickle cell disease

442 pediatric patients have HbSS

Male: female ratio is roughly 50:50

3 patients are of Hispanic ethnicity and the rest of the patient population is non-Hispanic African-American
Organization of SCD Clinics

SCD clinics divided by Age group (not therapy):
- Infant and Toddler Clinic: 0 to 5 yr 11 months
- School Age Clinic: 6 to 11 yr 11 months
- Teenager Clinic: 12 to 18 years

Frequency of Visits:
- < 1 year of age: every 3 months
- 1 to 2 years of age: every 4 months
- > 2 years of age: every 6 months
- Hydroxyurea therapy: every 1 to 2 months
- Transfusion therapy: every month or more often
Distribution of Patients
Population by Age

Type of Clinic

IT
299

SA
270

Teen
264

# patients
Multidisciplinary Approach

Developed to assist patients/families with the management of sickle cell disease, not only the medical management but the emotional and social impact of the disease.
Rationale: Patients with SCD have many complications throughout their lives demanding complex and integrated care. Integrated and multidisciplinary care should encompass the multiple dimensions of care of SCD.
Advantages

- Patient sees multiple members of the care team at one clinic visit

- Members of the care team are present in the clinic during the clinic hours and are “in sync”, i.e., constant communication with each other and the patient
Disadvantages

- The duration of the patient’s visit is longer (approximately 2.5 hours)

- Challenge to have all members of the staff “on the same page” (with a common vision)
SCD Care Team

- Physician
- Nurse Practitioner (NP) / Physician Assistant (PA)
- Nurse Case Manager
- Clinic Nurse
- TCD Examiner
- Social Worker
- STAR Coordinator (teacher)
- Research Personnel
- Genetics Counselor
- Pharmacist
- Child Life Specialist
- Nutritionist
Nurse Case Manager

- **Role:**
  - Centralizes and coordinates patient care
  - Each nurse case manager has ~ 200 patients

- **Prior to clinic:**
  - Reviews patient chart prior to clinic to assess patient’s needs and summarizes those needs
  - Sends summary to all member of the team (if necessary, addendums are made to the summary by other members of the team)
Contents of Case Manager’s Summary

Patient Name:
MRN: VISIT:
DX: DOB: AGE:

Medical Hx:
Social Hx:
Family Hx:
Family Studies: Mother: Father:
Immunizations:
Hospitalizations/ED visits since last clinic visit:
Last Clinic Visit:
Clinic Needs:
Next Visit:
Clinic Nurse

- Obtains vital signs, draws labs and assesses pain level
- Administers medication and immunizations
- Coordinates the individual patient appointments for the day
- Provides patient/family with information regarding their upcoming appointments
Nurse Practitioner/Physician Assistant

- Obtains patient’s history and physical-adjusts plan of care as necessary
- Coordinates patient’s care-monitor lab values, provide prescriptions, makes referrals
- Provides education
- Identifies potential research participants
Physician

- Oversees clinic
- Resource for NP/PAs and other members of the team
- Obtains patient’s history and physical examinations
- Highly involved with complicated patients and discussions with patients/families
- Discuss with patients/families available research projects and their potential involvement
During clinic

- Provides sickle cell education to patients and families
- Ensures all appropriate disciplines assess patient and facilitates the flow of patient care
- Schedules referrals and diagnostic testing as identified during the clinic visit
Social Worker

- Provides supportive counseling
- Identifies and overcomes the barriers to clinic compliance
- Links patients/families to available community resources
Transcranial Doppler Ultrasound (TCD) examiner

- Identifies patients in need of a TCD exam
- Performs the TCD exam in the clinic
- Provides education regarding the rationale for the TCD, potential results of the exam, stroke risk and the signs/symptoms of stroke
- Once read by the radiologist, notifies the MD/NP/PA of the results
- Contacts the family with the results of the exam
- Reschedules follow up exams
Success Through Academic Resources (STAR) Coordinator

- Teacher or counselor from the school system (Memphis City Schools)
- Identifies academic needs and deficiencies
- Works closely with schools to promote academic achievement
- Supports families in the investigation of academic options for their child
- Acts as a bridge for the medical and educational arenas
- Develops vocational plans for teenagers graduating from our Pediatric Program
Research Personnel

- Consent for studies with Principal Investigator
- Facilitate informed consent process
- Monitors research subjects-adherence to protocol requirements, and education for subjects
- Coordinates clinic appointments with the research requirements
- Obtains any additional labs or tests required by the protocol
Genetics Counselor

- For infants: the counselor educates parents regarding the inheritance of sickle cell disease (done in 4 phases) and their risks of having other children with SCD.

- For teenagers: the counselor educates adolescents regarding the chances of passing sickle cell disease on to their offspring.
Clinical Pharmacist

- Provides medication education and counseling
- Monitors medication adherence for patients on medication therapy (e.g., hydroxyurea)
- Fills and dispenses prescriptions
- Resource for clinicians
Child Life Specialist

- Provides emotional support/distraction for patient during invasive procedures
- Uses medical play to promote patient coping
- Prepares patient for upcoming tests (e.g., MRI, TCD)
- Provides developmentally appropriate diagnostic education
Nutritionist

- Assesses nutritional status of patients
- Identifies patients at risk for obesity and malnutrition
- Counsels and educates on nutrition
- Introduces nutritional research
Nurse Case Manager

- **After clinic:**
  - Provides summary of each patient’s clinic visit to all disciplines on team
  - Follows up on the referrals/diagnostic testing
  - Enters orders for next clinic visit

- **Preparation quarterly reports to state of TN and MS (# patients seen, diagnosis, outcome)**
Summary

- Every team member is important
- Viewing the patient as a whole not a disease
- Empowers patients/families with tools to cope with a disease with an uncertain course
- Multidisciplinary team approach to improve the patients/families quality of life