**Perception:**

Sickle Cell Patients have a higher degree of drug addiction than the general population.

**Facts** :

* The data regarding opioid addiction in patients with sickle cell disease provides less evidence for addiction than popular opinion would suggest.
* Prevalence estimates for opioid addiction among patients with sickle cell disease range from 0.5% to 8% vs 3% to 16% in patients with other chronic pain syndromes, and in the general population.
* Behaviors often described in patients with sickle cell disease, such as requesting a specific dose of opioid and requesting that the opioid be administered intravenously, may be normative in patients who have experienced a history of under treatment of pain . The following statement sums up the challenges that individuals with sickle cell disease have to confront in addition to the life threatening disease.

 **“Difficult patients are not just born, they are inpart, created by their passage through the medical system. Not only has this system failed to cure, it may have done unpleasant things to make matters worse”**

(Disorders of Hemoglobin Steinberg et al 2001-Pg 697)(Hartrick and Pitcher,1995) Fostering Trust and Justice William T. Zempsky, MD JAMA. 2009;302(22):2479-2480. Treatment of Sickle Cell Pain

**Patient Voices: Quotes and Insights from the Sickle Cell Patient Support Group**

 **“The pain is like a sledgehammer constantly hitting me up and down my spine.”**

**“Yes, I am a drug seeker. I need drugs to relieve my pain. I am not someone just seeking drugs.”**

**“If you have a cure for my disease, come in and talk to me. If you don‟t, keep walking.”**

**“When I’m in crisis, the pain is so severe that I really want to die. When I am home and feeling better, these thoughts go away.”**

**“Doctors and Nurses do not teach me about the disease; the disease teaches me.”**

**“I often ask myself, Why me God? and realize there are no answers.”**

**“I have goals and aspirations despite this disease.”**

 **“I have a 50% chance when admitted to the hospital that someone will be nice to me.”**

**“ Why did it take the hospital so long to recognize us. Is it because of who we are?”**

**What We Learned**

The majority of support group attendees never had depression screening or was referred to a psychologist or psychiatrist for therapy if needed

Improving patient trust is crucial to improving the lives of Sickle Cell patients.

Trust starts with a patient engagement philosophy that is non- judgmental

Effective Transition of Care process is important to patients and their families.

 Partnering with community based organizations Queens Sickle Cell Advocacy Network, under the Leadership of Gloria Rochester, President.

Sharing their experiences was crucial to helping each other in the broader context of the individual.

SCD like other chronic diseases does not have to control one's life.

Patients should make every attempt to control the disease and not have the disease control them.

Support groups give patients an opportunity to demonstrate who they are as individuals, voice their fears and share what’s important to the individual.

Listening to and understanding the individuals that participated in the The Sickle Cell Patient Support Group changed the negative perception to the reality as to who these individuals human beings are. They taught us about who they are,encouraged us to understand their fears and know what’s important to them and to acknowledge that they have dreams and aspirations like other human beings as well.The words drug seekers were never used going forward.

 To this day treatment of Sickle Cell Patients is a priority at Queens hospital. I recently spoke with Dr. Dave Holson,who was then and current Medical Director, Queens Emergency department and very supportive of the initiative concerning Sickle Cell patients.

 He stated that readmission was significantly down, patient engagement and collaboration was up and contentiousness between staff and patient has been eliminated . Currently there is a Physician Assistant assigned for all emergency visits and the use of the observation unit has proven to be effective.

**For all hospitals that treat individuals with Sickle Cell Disease, I would really recommend adaptation of the following processes for Adult Patients**

1. Formation of a Sickle Cell Patient Support Group for Patients in the ED and those admitted organized by the Care Management Department in your institution.

2. Have care,case managers obtain consent.

3. Collaborate with the ED and In-Patient Medical Director, Hematologist, Nursing Supervisor and Psychologist and Social Worker.Staff should attend the support group as well.

4.Schedule meeting around lunchtime if possible and provide lunch

5. Develop a patient registry that identifies race, gender,age primary language and country of origin.

6.Get feedback on mandatory depression screening.

7. Discuss with the ED Director, the pain management requirements listed in the electronic medical record for each patient including on a continuous basis, patients who transition from adolescent to adult care.

8. Discuss possibility of clinical trial participation including Stem Cell Treatment

9. Total elimination of the word “DRUG SEEKER”

10. Individuals that graduate from high school and who will be attending college, including out of state should be recognized at a celebratory event.

 In addition, have an education seminar scheduled concerning the topic of insurance coverage, transfer of medical records, hospital information about treating patients with Sickle Cell Disease.

11. Have Health plans do an inservice for staff and patients about health coverage as one transition to an out of state college.

**For Children and Adolescents with Sickle Cell Disease:**

1. Develop a registry as well.

 2.Implement a Sickle Cell family support group

 3.Included in the support group should be a psychologist and social workers.

 4.When transitioning to Adult care have the adolescent doctor, patient and family meet with the adult provider and transfer information as well as who is the Individual and not just who is the patient. Share the medication and dose that’s known to help and is needed when a patient is in a Sickle Cell crisis.

5.. Discuss requirements of clinical trials and Stem cell treatment.