ELIMINATING DISPARITIES IN CARE

Case Study: Sickle Cell Disease Clinic

Project goal: to help sickle cell patients manage their disease and decrease the need for emergency hospitalization.

Reason for project: to create a dedicated, patient-centered medical "home" for sickle cell patients where they can access both urgent and routine care.

Demonstrable outcome: Over the last three years, roughly 20 percent fewer Clinic patients access care through the emergency department.

Sustained accomplishments: With help managing their disease, clinic patients are now able to hold steady jobs and stay out of the emergency room.

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Organization: Truman Medical Centers (TMC)

Program: Sickle Cell Disease Clinic

Location: Kansas City, MO

Summary: Sickle Cell Disease is an inherited blood disorder that affects red blood cells. These cells become sickle-shaped causing them to block small blood vessels. Without normal blood flow, tissue becomes damaged resulting oftentimes in serious, life-altering complications.

Sickle Cell Disease can cause anemia, jaundice and the formation of gallstones as well as lung tissue damage (acute chest syndrome), pain episodes (arms, legs, chest and abdomen), stroke and priapism (painful prolonged erection). It also causes damage to most organs including the spleen, kidneys and liver.

In the United States, sickle cell disease affects primarily African Americans and there is no universal cure.

The goal of the Truman Medical Center (TMC) Sickle Cell Clinic is to provide both a patient centered medical home and a multi-disciplinary approach to the treatment of adult sickle cell disease. A dedicated care team focuses on improving the quality of life of those with sickle cell disease through health maintenance, education and patient support. All patients receive a comprehensive evaluation and treatment plan designed to meet individualized needs.

NOTE: Some programs are in the initial stages for data collection and reporting, while others are small in scope and have not yet established benchmarks. Where there is data available, it is provided in the questions and answers below.

Q&A:

1. How did the organization's leadership know there were disparities in care, i.e., clinical

TMC historically treated patients with sickle cell disease out of the hematology/oncology clinic, however, sickle cell patients continued to go to the emergency department when in crisis and felt there was not a focus on their disease process or unique needs. It was then in 2005 that TMC CEO John Bluford was approached by a group of patients who felt more could be done to address their individual and community needs related to sickle cell disease. Mr. Bluford met with sickle cell disease patients, family members and neighbors in a group setting and discussed the positive and negative aspects of their care at Truman Medical Center.

Following these conversations, TMC created a dedicated, patient-centered place where sickle cell patients had care providers that understood their unique situations, needs, conditions and how best to manage the disease.

2. How did the organization plan interventions and implement the program?

The Clinic's goal is to more effectively and efficiently manage patients' needs, reduce episodes of crisis, and thus mitigate the severity of complications. Inherent within this goal is a decrease in the need for emergent care and inpatient admission.

One component of achieving this goal is comprehensive disease management education to both the patients and the clinical staff.

Educating patients – All primary care physicians instruct sickle cell patients to come to the Clinic versus the emergency department when possible. Prior to discharge from the emergency department, outpatient or inpatient setting, physicians ensure that all sickle cell patients are made aware of the Clinic's services and benefits of utilization. Additionally, all newly diagnosed sickle cell patients are offered a referral to the Sickle Cell Clinic.

Educating Medical Staff – Sickle cell education is regularly provided to medical staff through staff meetings, grand rounds, noon educational conferences, and consultation. All members of the sickle cell team are always available for consultation across the continuum of care.

As a teaching institution, it is important to educate the residents and students as residents are frequently the first line of care. Well educated residents are instrumental to ensuring appropriate and timely sickle cell interventions.

3. What was the time frame, from conception to full implementation?

Immediately following the initial meeting with patients, families and neighbors, TMC began working on developing a patient-centered environment and approach to care. One year following the focus group meeting, TMC had in place a new medical home dedicated to sickle cell patient care.

The patient-centered services and dedicated space include:

- Comprehensive disease management, including annual exams, pain control, nutritional counseling, physical therapy, lab and x-ray evaluations, lifestyle education and emotional support.
- Individual treatment plans specific to patient's age and disease stage
- Urgent care clinic as an alternative to the emergency department
- Patient waiting room with color and light schemes that help stimulate healing and comfort
- Exam rooms centered on comfort with soothing lights and décor
- Counseling not only for patients but for family members as well

4. What were the results?

Over the past three years, the Clinic has seen roughly 20 percent or less of sickle cell patients driving emergency department visits; while the majority of patients are receiving both urgent and routine care through the Clinic. The key driver in the Clinic's improvement efforts has been the focus on providing a comprehensive medical home for this patient population. Previously, these patients were simply treated along with the general population by staff that did not have the comprehensive understanding of sickle cell disease management.

5. How did the organization assess the outcomes?

TMC began formally tracking sickle cell patients since the formation of the Sickle Cell Clinic. A nurse practitioner is dedicated to case manage sickle cell patients across all care continuums. The sickle cell care team tracks the reasons for emergency department visits and inpatient admissions and works to adjust their care plan to help each patient more effectively manage their disease and reduce the need to seek hospital acute care services.

6. Has there been a sustained improvement since implementation?

Clinic staff regularly hear stories of lives that have been changed. Before the Clinic, patients found themselves in and out of the hospital. Now, many are able to hold steady jobs, have families and are able to live a full life while managing their disease.

Over the last two years, growth in average Clinic visits has increased. Patient surveys report high satisfaction regarding the care received within the Sickle Cell Clinic.

7. Is the program part of the hospital's quality improvement goals?

The Sickle Cell Clinic participates in the TMC Quality Improvement process. One of our major PI projects this year is to decrease the inpatient and ED readmission rates by actively engaging the patients in the clinic process. No one from the QI Department participates in the Clinic's management in a direct fashion. However, the clinic certainly participates in all Quality initiatives coming from the Quality Department, for example: regulatory requirements, quality improvement reporting, patient safety goals, etc. Also, TMC does have Lean / Six Sigma Black and Green belts based both in the Quality department and in other locations throughout the organization, including Ambulatory care, which assist on PI projects as necessary.

8. What challenges or obstacles were overcome?

It is a complex and difficult patient population to case manage and an ongoing challenge to build and maintain a trusting relationship. Managing care within this medical home model creates an environment that more effectively fosters communication, partnerships and ultimately trust between the patient and care providers. Consistent knowledgeable clinical staff is critical for these patients as well. They need to see the same faces and be reassured that their clinicians understand their disease and needs.

The Clinic is open from 8:00 a.m. to 4:30 p.m., five days per week, but sickle cell crises do not just occur between these hours. 60 to 70 percent of sickle cell related admissions occur when the Clinic is not open. If the Clinic was able to manage these sickle cell crises within the Clinic setting 24/7, reduced admission rates and better quality of life would be expected.

However, given the limited hours of the Clinic, a strong partnership with the emergency department is critical so that ED staff is continually sensitive to the specific needs of these unique patients.

Additionally, just one day of Clinic pain management treatment, which historically led to inpatient admission, is oftentimes not enough. This trend prompted the Clinic to change its practice and offer patient treatment over multiple consecutive days. Patients will go home at night to rest, and then return for more treatment the following morning. This gives the patient freedom and control over their time and has helped decrease inpatient admissions.

9. What was the cost of the program (grant, etc.)?

There was an initial investment of approximately $150,000 for the Clinic space.

A Health Care Foundation grant and HRSA grant were obtained to subsidize sickle cell disease services including staffing, education and support groups.

10. What other stakeholders (i.e., community groups) were involved?

TMC has informal partnerships with the regional chapters of the Sickle Cell Disease Association of America in the form of community event support, patient referral and staff education. Community groups support the Clinic through other special events for patients and their families. In particular, Kappa Alpha Psi Fraternity Inc. has hosted two holiday parties for sickle cell patients and their families. Along with the party and gifts for all children in attendance, the fraternity has given a gift to the Clinic. In 2006 a refrigerator was given, last year the fraternity gave portable DVD players.

A relationship with Scandia Down, a local luxury linen store, was also developed which resulted in the donation of high end linens for all patient beds in the Sickle Cell Clinic.

One goal for the Clinic is to increase collaboration among groups with whom TMC has existing, strong relationships. An example is the local black church coalition , a group the Clinic successfully partners with for other initiatives. The Clinic also works closely with the adjacent children's hospital to facilitate the transition of care from childhood to adult treatment.

The Clinic also has a partnership with the State of Missouri which provides for parents of sickle cell babies to receive genetic testing.

11. What advice would you give other organizations wanting to improve care in similar ways?

There is a need for patient centered, disease specific programs to be built around the unique needs of this patient population. Not enough emphasis can be placed on taking the time to listen and understand the perspective and unique needs of these individuals and their families.

It is important to involve all internal and external key stakeholders and to provide continual education throughout the hospital or system so appropriate care and referrals occur across the continuum of care.

Critical to the success of each patient's disease management is the development of individualized treatment plans which are available to and applied in all care settings. Patients report that this care approach helps to meet both their physical and emotional needs.