Sickle Cell Ch. 2

**Sickle Cell Disease Series: How Atrium Health is helping to create continuance of care for Sickle Cell Disease patients as they move into adulthood**

Thanks to medically-advanced, life-saving treatments, sickle cell disease patients are living longer and better lives. However, there is still a nationwide shortage of physicians and researchers who focus on making continued medical improvements in the sickle cell disease population. Traditionally, a primary care physician cannot fully treat a sickle cell disease patient; the disease requires a specialist.

Most sickle cell disease patients are treated by pediatric specialists until they are 18. Then, as often happens in the case of complex diseases, the patient falls in between the treatment cracks. They’re in college or working, and maybe not on their parents’ health insurance anymore, so they don’t actively seek preventative care and other necessary screenings. They end up being treated in the emergency room, and sometimes admitted to the hospital for days and weeks just to control the pain, not even to address the other symptoms and illnesses sickle cell can cause.

Ifeyinwa Osunkwo MD, MPH, is particularly passionate about helping this young and at risk population. Dr. Ify, as she prefers to be called, is a hematology specialist with Atrium Health’s Levine Cancer Institute.

She is the Principal Investigator for the Patient-Centered Outcomes Research Institute (PCORI) grant which Atrium Health was awarded in September 2017. The $9.8 million grant is allowing Atrium Health physicians and specialists to compare strategies to improve care-management transitions for adolescent and young adults.

“We are the forefront of this groundbreaking intervention for young adults with sickle cell disease for the first time ever in this country,” said Dr. Ify.

The PCORI grant allows Atrium Health to partner with programs across eight states; North Carolina, South Carolina, Georgia, Florida, Alabama, Kentucky, Virginia and New York. The programs include pediatric programs, adult programs and community-based organizations. A medical team will work with patients for at least two years as they transition from pediatric care to adult care, helping avoid the lapse in care at a crucial time.

“We're looking to see if we will improve their acute care utilization, their quality of life and how much time they spend in the hospital,” said Dr. Ify. “We will also be tracking how sick the patients get over their time in the programs as well as program participants’ mortality rate.”

Through standardizing care, the hope is that patients will get the same treatment and ultimately be healthier, explains Dr. Ify. They will add a peer mentor project to the treatment plan as well to see if that helps improve outcomes.

This project has been in the works for more than four years. When Dr. Ify was recruited from Emory University Hospital in Atlanta to come to Atrium Health, known then as Carolinas HealthCare System, she noticed a trend of patients spending a lot of time in the hospital for treatment. She was recruited because the sickle cell population needed more attention. So, together with a medical team, Dr. Ify started with the sickest of the patients, those in the ICU and ER, which is the last place a doctor wants a patient to end up. They then moved the focus to patients who were sick but out of the hospital. The need for a specialty outpatient clinic was fully realized once it was opened.

“We built a clinic in April 2014 and over the past four years, we’ve seen at least 400 patients in the clinic,” said Dr. Ify. “We started seeing patients every month, every two weeks, we had some people who were coming every week; every single week for a very long time.”

The medical approach was a multi-disciplinary model to figure out the patients’ main issues, which range from medical and social issues to psychosocial, emotional, physical and psychiatric concerns. Having access to a wide range of physicians and specialists in Atrium Health’s system, the patient population has vastly improved. The readmission rates are lower, patients are more satisfied with their care and more people are engaged in and knowledgeable of sickle cell disease.

Dr. Ify is also a big believer in diet and hydration to help manage sickle cell disease symptoms. She often challenges patient to water competitions to encourage them to drink more water on a daily basis.

Atrium Health is participating and engaging in clinical research and clinical trials in the treatment of sickle cell disease. Part of that research involves the development of an app specifically for sickle cell disease patients. The app is just starting internal testing in October 2018. The idea is that patients will use the app daily to track pain levels, water intake and medication administrations. By logging these reports, patients and their providers will hopefully be able to identify trends that produce medical crisis and help prevent those in the future.

*Patient Spotlight*

*Shirley Miller, an Atrium Health teammate and program manager in the sickle cell disease program, is also a sickle cell disease patient. Diagnosed when she was three years old, Miller was told she wouldn’t live to be 21 years old.*

*“At the time when I was born, they really didn't know a lot about sickle cell, so it was a lot of*

*trial and error trying to figure out really what was my diagnosis and what was going to help me,” said Miller. “I did spend a lot of time in and out of hospitals, being stuck with a lot of needles and in a lot of pain. And so it took a while for my family to even figure out what it was that I had and how to manage the disease.”*

*After beating the odds, in her 30s, Miller decided she needed to be a community advocate for the disease, based in her new hometown of Dallas. She spoke at national association conferences which is where she met Dr. Ify.*

*Dr. Ify eventually hired Miller as a program manager with Atrium Health in Charlotte. Miller was drawn to Dr. Ify’s assistance in transitioning pediatric patients to adult patients in the sickle cell disease process, especially since she didn’t have that as a pediatric to adult patient herself.*

*“She's great when it comes to transition, moving people from pediatric to adult care,” said Miller of Dr. Ify.” She's one of the leading doctors in sickle cell. She's very good.”*

*Miller wants fellow sickle cell disease patients to know that the disease can be managed if you follow the instructions of your doctor.*