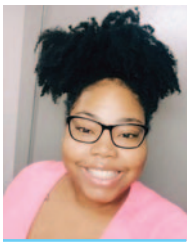

Guest Editorial

Cyara Bond

My Story as a Patient with Sickle Cell Disease

Bond, C. (2020). My story as a patient with sickle cell disease. *Pediatric Nursing, 46*(6), 265.

What is sickle cell disease? By definition, sickle cell disease (SCD) is an inherited blood disorder characterized by chronic anemia and periodic episodes of pain. This disorder affects over 72,000 Americans and millions throughout the world, most of whom are of African descent. Approximately 1 in 13 African Americans carries the trait for SCD, and 1 of every 365 African American infants is born with the disorder (Centers for Disease Control and Prevention, 2020); the incidence of the disorder in Africa is 10 times higher than in the United States (Mulumba & Wilson, 2015).

Persons with SCD inherit defective hemoglobin genes from both parents. Sickled blood cells can block blood flow, causing pain and/or injury to important organs. The pain can last for days or weeks and is called a vaso-occlusive pain crisis. Unfortunately, this definition does not define how it affects a person's emotions, feelings, or their lives.

How does it affect me? My name is Cyara Bond. I just turned 21, and SCD affects my life daily. I am from Columbia, Tennessee, where SCD is not well known. It is hard for me to go to the hospital in my local area when they know nothing about my sickness. I have also been judged by health care providers plenty of times. Sometime us "sicklers" need large amounts of medicine for our pain to go down. Unfortunately, in today's world, there are people who go to the hospital saying they are in pain when it's not true—a form of drug seeking. Despite the illness that causes my pain, I have been called a drug seeker or an addict. I have also been accused of lying about my amount of pain.

As I have gotten older, the vaso-occlusive crises last for weeks upon months for me. SCD affects all patients differently. I can only testify for myself. Just this year alone has been my longest time in the hospital. While in the hospital, you can come across many different patients in the same boat as yourself.

Sickle cell disease comes with many symptoms. Even before COVID-19 came along, avoiding infections and getting regular vaccinations were already a part of our yearly lives as people with SCD. Pain can make you feel fatigued. You can get triggered into a pain crisis with dehydration, extreme weather, alcohol, smoking, and emotions or stress.

Emotionally, life with any type of sickness is overwhelming. The stress is sometimes too hard to bear. You can't fix it, your family can't fix it, and even your nurses who are seeing the pain and distress on your face daily can't fix it. My pain attacks me randomly. This year, for five months, I was feeling stuck in a hospital. I was feeling frustration, irritation, and so much more. The doctors, nurses, and everyone who provides your daily care gets frustrated. They seem to wonder why you are in this amount of pain and why they can't fix it.

Medicine-wise, the pain medication can make you groggy, irritable, sleepy, etc. Sometimes I turn the feelings of my frustration toward the ones closest to me. No one understands the amount of pain I'm in. I get tired of taking all these forms of medication. I now take 12+ medicines.

My friends and family are very reliable people. For some patients with SCD, that's not the case. We get accused of faking our pain a lot when that's not the case, and the pain gets worse as we get older. Our bones weaken, our organs are at risk, and our immune system is forever at risk. It's lower than the next "normal" human. Most of the time, we go through our hospital visits ourselves. It's a very hard time.

At times, nurses become our very own daily friends or sometimes our foes. If the four walls in our hospital rooms could talk, they would say a lot. Our hospital experiences would be great if there were nurses who didn't allow their own emotions and judgments to affect our care. It's okay to have a bad day, but don't bring it in to work. That not only applies to nurses, but anyone in the work field, but more towards the medical field. Unfortunately, I have been cared for by a racist nurse, nurses who didn't want to give me medication that was needed because they thought it was too much, nurses who never helped change my bed sheets, nurses who were agitated that I needed something from the pantry, or just needed help in any way shape or form. It made me feel unwanted.

All in all, please watch the way you handle any type of patient. It could be your family member, friend, or stranger. Be kind to anyone who is sick, not sick, total strangers, or anyone. Please remember that every human has emotions. Your words and looks can really affect people who are living with illness and pain.

Cyara Bond *lives in Tennessee and is studying to be a forensic pathologist*

Editor's Note: *As a holiday gift to our readers, we continue our annual tradition of turning over the November/December editorial pen to a child or young person. This year we are most grateful to have Cyara Bond, who shares her personal experience with sickle cell disease.*

References

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