Sickle Cell Disease and the Monster Called ’Pain Crisis’

November 28, 2014 By Cyntra Scott

I decided to use this post to focus on the pain that accompanies having sickle cell anemia. Many people associate sickle cell disease (SCD) mostly with the anemia part, being tired and weak because of SCD. This fatigue, a feeling of tiredness and exhaustion, and, at times, even feeling fragile are true and valid concern. But the painful sickle cell episodes (called a vaso-occlusive crisis) is the hallmark of the disease.

Just yesterday I woke up tired, sick and in pain. But, this time, the pain was manageable. Still, I couldn’t walk and so I had to stay in my bed for the majority of the day. Essentially, SCD held me hostage for one whole day. I couldn’t work or attend a meeting that I had scheduled. For me, the immediate feeling was to get highly frustrated and upset. But if I gave into these feelings, this would undoubtedly send my pain into a worse direction. Stress is a major trigger of a SCD pain crisis, so this must be avoided.

When I find myself in this situation, I turn to a rather helpful and supportive Facebook group called Sickle Cell Unite. I belong to this group and this is where I go to make comments, complain, ask questions, express thankfulness and get support. So I asked a question: “How would you describe sickle cell in five words or less?” What follows are are some of the answers I received: “Excruciating to body and soul”; “Stress and wears body down”; “A mind of it’s own”; “It’s worse than childbirth”; “Fire in my blood”; “Hurts like hell”; “Stabbing all over your body”; “Pain of death”; “Death”; “Pain from the bowels of Hell”; “Is the F**king devil”; “Burning on the inside”; “How is this even possible?”; “LAWD take me now pain”; “Lord take this pain away”; “It’s very, very, very unbearable”; “Sickle cell go home you’re drunk!”

During an interview of a friend of mine with SCD, I asked him to describe the pain. He simply stated that there would be no point because it’s so excruciating that people would be unable to grasp the extent of it.

Why SCD hurts physically.
The sickled blood cells are shaped like a farmer’s sickle or a banana. The edges are rough and they are very sticky. Unlike normal round, smooth and slippery red blood cells, sickle cells clump together causing clogs within the veins. The smaller veins, the capillaries can burst which causes additional complications beyond pain.

But the interesting thing I find with having SCD is that you can feel rather well or “normal” at times and then by the next day, in an hour, or even a minute, your body can be riddled with severe pain. A sickle cell crisis doesn’t follow a time schedule. This means that anytime or anyplace is open season for the onset of a pain crisis. I remember one episode in particular that happened when I was a teenager. I went to the movies with my friend and started to feel cold in the theater. But I didn’t let the feeling phase me. About 15 minutes later, however, I felt the pain start in my ankles and then that feeling escalated rapidly.

My friend and I walked out the theater and the pain worsened when I made the transition from being in the cold of the air-conditioned theater then moved into the hot summer night air. Before my mom could come to pick us up, the pain increased to an unbearable level and I fell onto the sidewalk. There was a crowd of people in line for the movies and I was very embarrassed. But the pain was greater. A police officer came over and stayed with me until my mom arrived about 10 minutes later. That pain crisis lasted for a week. Ever since, I always have a sweater with me when going to the movies.

Yes. There are measures we can take to try and ward off or lessen the impact of a crisis. To do this, it's key we know what triggers our sickle cell crisis. Parents of young children should teach them how to recognize their triggers, and arm them with ways to avoid these pain starters. Although sickle cell crisis triggers vary from person to person, the most common ones include the following inciting incidents: hot and cold temperatures, seasonal changes of weather, colds and the flu, over-exertion, dehydration, infection and stress.

As you can see, there are many challenges associated with living with sickle cell. I find that when dealing with pain crises, the hardest part is during the minutes to hours when you recognize that you are in fact really going into a full-blown, off-the-pain-scale chart sickle cell pain crisis. That's when the big challenge is to breathe and actually stay calm in the midst of the jabbing, stabbing, throbbing, wringing and wrenching pain. Meanwhile, you're also thinking of what you should be doing (working, studying), who you should be taking care of (children, parents, spouse) and knowing that you can't do anything else but cry and curl up into an often awkward and contorted position for the slightest relief.

SCD is very intense and tricky to live with. But that's not to say that I am underestimating the rigors of any other chronic illness. This is my way of highlighting the pressures and variances of SCD. A crisis can be brought on by a variety of triggers and last from 2 to 21 days. The pain can vary drastically in frequency and intensity throughout one's lifetime. Simply put, a sickle-cell crisis affects our lives enormously. For those of you who want to know what having a sickle cell crisis actually is like, imagine sitting down at your computer surfing the web or doing work and then within the first hour starting to feel some kind of ache or pain. Then, within 20 minutes of feeling that initial slight pain you get clobbered by two large bodybuilders punching you, kicking you, slamming you against the wall, and stabbing you intermittently. Excessive? Not really because this describes a really terrible sickle cell crisis. This type of pain can literally last for days despite downing strong pain medication prescribed to reduce and dull this excruciating assault on your body.

But on the bright side, people living with SCD aren't always in a state of a sickle cell crisis. We do enjoy days when we feel relatively well for weeks or months. These are the days I like to focus on, and I encourage everyone living with SCD to focus on these good, pain-free days too.

In an upcoming post, I'll bring you advice from a few outstanding nutritionists on how to eat well with sickle cell. As always, be encouraged, empowered, invigorated and inspired.

Be well! Be wonderful!
