Feel My Pain Podcast

Ep. 2 Script – “Crisis Away from Home”

Sponsor Message

Intro

Welcome to “Feel My Pain,” a podcast that raises awareness by sharing real stories of those impacted by Sickle Cell Disease. I’m Sola, and today we are talking about the time I had a Sickle Cell crisis while living out of state and away from family.

Vocab Word

Hey fam! Welcome back! Before we jump in, today’s vocabulary word is “Crisis” (singular) or “Crises” (plural).

You’re probably already familiar with the word crisis. Generally, we think of a crisis as an event marked by intense difficulty or hardship. This definition holds true for those with Sickle Cell Disease, however, crisis has a deeper meaning in the context of Sickle Cell. Sickle Cell is marked by chronic, physical pain. Episodes of pain are often called crises, Sickle Cell crises, or pain crises.

According to the Mayo Clinic, “Periodic episodes of pain, called pain crises, are a major symptom of sickle cell… The pain varies in intensity and can last for a few hours to a few weeks. Some people have only a few pain crises a year. Others have a dozen or more pain crises a year. A severe pain crisis requires a hospital stay. ” (2021). Basically, episodes of pain can be described as mild, moderate, or severe pain crises.

Topic Discussion

Now that we got that out of the way, I’m going to tell ya’ll about the time I had a severe pain crisis away from home.

Background Info

Okay so I live in Maryland, born and raised. In the past when I have had severe crises, I have typically been admitted to a local hospital. From childhood, my go to hospital was Children's in Washington, D.C. which has exceptional experience, understanding, and treatment of Sickle Cell Disease. When I transitioned out of pediatric care, I would report to Howard County General Hospital, which, at the time could use some work in the treatment of Sickle Cell patients. I've also received care at various Kaiser Permanente facilities which have consistently been incredible experiences. I can say the same about Holy Cross Hospital in Germantown, which I've been admitted to a few times. *Chef's Kiss* extraordinary care. My most recent hospitalization was at Doctors Community Hospital in Prince George's County. I had a terrible experience there, but I'll share that story another time. So that's a little background information on the local hospitals I have been admitted to in and around Maryland.

As far as out of state, I have actually had a few crises while living away from home in both Texas and Virginia. My most recent out of state hospital admission was in Reston, Virginia, and that's what we're going to talk about today.

In April 2018, I moved to the Reston/Herndon area to attend an IT bootcamp. It was an opportunity for me to develop my skills and eventually be matched with an organization and begin a career in the IT industry. The program required everyone to relocate to Reston. During the work day, we had extended instructional sessions and opportunities to collaborate to implement the concepts we were learning. At the end of the work day, it was highly encouraged that we return to our respective housing and dedicate our evenings to studying and practicing, so you can imagine how intense the program was.

On top of all of that, I did not have a car at the time, so every week I would rent a Turo. Turo is a carsharing platform and app that allows you to rent cars from individuals within your surrounding community. I was a little short on change during the time, so I would rent Turos to cover the commute from my housing to the office and use the Turos to deliver food through DoorDash during the evenings to make extra money and support myself.

The Crisis

Between moving, bootcamp, studying, DoorDashing, and all the transition happening in my life, the physical demands on my body increased greatly and I experienced a lot of stress, which is one of the causes of Sickle Cell crises. The week leading up to May 12th, I could feel and sense that my body was becoming more vulnerable and I attempted to pace myself, but my mild pain increased rapidly.

So on Sunday, May 13, 2018, I was due to return a Turo I had rented for a week. However, on Saturday, the 12th, I woke up in pain. Severe pain. The pain was affecting both of my legs, but it was worse in my right leg. So much so, that I couldn't really walk or function normally. While in tears, I called my mom to help me decide what to do, considering that I needed to return the Turo to the owner the following day. She forcefully encouraged me to drive myself to the hospital and we could work out the rest later.

My relocation to Reston came about pretty quickly and, at the time, I had not had many severe pain crises, so, prior to moving and starting my bootcamp, I did not prepare myself for a possible crisis. That was my first mistake. Quick tip: If you have a severe medical condition, always have a plan of action for a possible medical emergency, especially while traveling or when moving. It's important to research and locate a physician or medical facility that can address your needs ahead of time so you don't have to worry about finding one in the midst of an emergency. You can even ask your primary care physician to refer you to another doctor. My mother helped me do this when I moved to Texas in 2011 and it benefitted me immensely.

So, because I hadn't accounted for a place to receive care ahead of time, while crying and experiencing the pain of my crisis, I literally had to strain to find my insurance card and call the insurance company's customer service line to find a hospital that would be able to treat my crisis. When you're having a crisis, time is vital, so I could have used this time to get to the hospital and receive care faster.

After locating the hospital, I quickly packed a bag in preparation for a hospital stay, made my way to the car, and drove myself to the emergency room. Imagine you just sprained your left leg, and broke your right leg, and you're on the third floor of a townhouse with no one home to help you. Once you drag yourself all the way downstairs, you have to get yourself in the car and use your broken right leg to drive yourself to the hospital safely, find parking, and use both of your injured legs to walk yourself from the parking lot into the emergency room, all while trying to manage the excruciating pain coming from your legs.

So you can imagine that once you walk into the emergency room, you expect to receive emergency care, right? You anticipate relief, right? Welp, that's not always the case as a Sickle Cell patient, especially as a person of color and first-time patient in a foreign city and state.

Emergency Room Experience

I walked into the emergency room, writhing in pain and sat in from of an emergency room receptionist. She asked me what was wrong and I basically told her I was having a severe Sickle Cell crisis and needed immediate care. She looked me with a blank facial expression as if what I just said was of no significance to her and proceeded to ask me the rest of the questions they typically ask you in the ER.

After answering her questions, I was told to have a seat in the waiting area until I was called on to be seen. Best practices while treating a Sickle Cell patient in ER include recording their vitals which include temperature, blood pressure, pulse and respiration rate immediately and assigning them a room as soon as possible. As stated before, with Sickle Cell, time is vital because complications from a severe crisis can escalate quickly. Typically, Sickle Cell patients that come into the ER should not have an extended waiting period. We're usually bumped to the top of the ER waiting list.

Don’t get me wrong, I have had a few experiences in which I had to wait longer than I am supposed to due to the amount of patients coming into the ER, but even in those cases the hospital staff understood what Sickle Cell Disease was and did what they could to treat me accordingly. Unfortunately, in this case, the staff treated me like I was a joke.

The waiting room only had a few other patients so, from my perspective, it was possible for me to acquire a room and be seen by a doctor in a timely manner. However, the medical assistants delayed my care by asking me a number of questions repeatedly over periods of time, as if to test the validity of my statements. It didn’t matter that I was crying and visibly experiencing immense pain, they kept me waiting. I observed their interactions with other patients and noticed that other individuals who walked into the ER received better treatment. The staff was not responsive to me and my requests at all. One medical assistant looked confused as I explained to her that I have Sickle Cell and was experiencing a severe pain crisis. It was as if she didn’t even know what Sickle Cell was.

Shocked and in pain, I quickly understood that the people that were supposed to help me did not believe me or even care about me. Their interactions with me were extremely rude and insensitive and their nonchalance was evident. They were cold and unemotional.

Sadly enough, this happens too often. It is not uncommon for medical staff to view Sickle Cell patients inaccurately. There are countless stories and testimonies in which patients describe being met with ignorance, unbelief, prejudice, and discrimination while having a pain crisis. Many individuals with Sickle Cell have been viewed as drug-seekers, resulting in delayed care and ill-treatment which impacts their health and recovery directly. In a 2016 Johns Hopkins article by Vanessa McMains, McMains states that “one of the biggest challenges in sickle cell disease is that clinicians may not believe patients are in pain when there aren’t any signs of tissue damage or believe they are drug-seeking, and thus contribute to suffering.” Sickle Cell is almost like an invisible disease, as everything happens internally. Often times, medical staff choose not to believe what they can’t see externally.

In some cases, medical professionals may not be treating Sickle Cell patients from a place of discrimination. However, they may not have the proper knowledge, training, and experience to treat Sickle Cell patients confidently and successfully. Generally speaking, in the medical field Sickle Cell Disease deserves more recognition, attention, education, research, and funding. Quick plug: for more on this, I suggest tuning in to an episode called Sickle Cell + Racial Injustice (Feat. Dr. Ahmar Zaidi) from The Sickle Cell Podcast.

So let’s get back to my ER experience. I’m in the emergency room, experiencing a crisis, trying to convince medical staff that I need to be seen and treated as they remain unresponsive and delay my care. After a little over an hour of waiting, I am finally assigned a room and escorted to the back to get treatment started. Unfortunately, even while being cared for I still have to fight with the medical staff.

When I am experiencing a severe crisis, I am typically treated intravenously with Dilauded or Hydromorphone, Hydrocodone, Oxycodone or something similar. Heavy stuff, right? Unfortunately, I am allergic to Morphine and Toradol, which are some of the go to drugs for Sickle Cell patients.

I requested the pain medication I typically receive, but the individual treating me decided to overlook my request and start me off with high doses of ibuprofen (commonly known as advil or motrin). More time goes by and, no surprise to me, the ibuprofen doesn't help. I tried ibuprofen before coming to the hospital and I knew it wouldn't help, but the medical staff trusted their judgement over mine. After finding that their first attempt was ineffective, the individual suggested Morphine. I'm allergic to morphine, which I explained previously, but I suppose they did not believe me and thought I wanted to surpass Morphine for harder drugs. In an attempt to request Dilauded again, I was met with questions about how I react to Morphine and more unbelief. I answered this question before, but answered it again with frustration while my care was delayed further. After answering, I requested Dilauded once more. The individual said they would go talk to their staff to determine the best treatment method for me and come back with answers.

The more time spent in the emergency room without being treated effectively means it will take more time to be admitted to the hospital where patients receive optimal treatment. Delaying care causes a prolonged crisis and, with all this back and forth, my pain was not getting any better. Finally, after an additional 30 minutes or so, the individual returns to inform me that I can finally receive the Dilauded I had previously requested. Things were finally looking up. My body eventually started to respond to the medicine and I was admitted to the hospital and transported upstairs to continue receiving care, however, the battle did not end there.

When I got situated in my official hospital room, I experienced multiple challenges. My nurses did not check in on me consistently, which is imperative when treating a Sickle Cell patient. Medication I was supposed to receive on a strict schedule was delayed or forfeited altogether, which meant the intensity of my crisis fluctuated. Furthermore, it was a pain to simply request for and receive heating packs, which help treat some of the discomfort. The medical staff was rude and disorganized. I could tell that they did not communicate with one another, which is essential when taking care of someone with Sickle Cell Disease. I was constantly repeating myself over and over again to various clinicians, which is stressful to do while experiencing extreme pain, fatigue, and the effects of the medicine. Altogether, I felt insignificant. This went on for the rest of the evening into the next day, until my mom showed up.

Throughout my life, my mom has been my main advocate. She knows the ins and outs of my health, my treatment, everything. I could just glance in her direction or call her and say, "hi," and depending on my facial expression or the sound of my voice, she'll know whether or not I am in pain. Furthermore, she's a medical professional, a Sickle Cell expert, and when it comes to my health, she knows how to get things done. I admire her ability to walk into my hospital room, speak to the hospital staff in medical jargon, vouch for me, and put people in their place where needed. She's always been my personal superhero.

So my superhero arrives on Sunday, May 13th to save the day. First, she helped me return the Turo. On Sunday afternoon at 2:10pm, I sent a message to the owner of the rental car, saying,

"Hey Mohamed! Hope all is well with you.

In the past couple days I got sick and ended up being admitted into the hospital. I drove myself to the hospital in your car. I was hoping I'd be able to leave today, but my doctors think it's best for me to stay.

My mom is currently on her way to visit me. She is willing to pick up the fusion and return it at our scheduled return location & time.

I was wondering if you'd be alright with her doing so? Also, will you be there to meet her when she drops off the car or would you rather she leave the key in the glove compartment in the same manner you left the key for me?

My apologies for any inconvenience and thank you again for making your car available for me to drive this past week."

Two minutes later, he responded with, *"Wow I'm so sorry to hear that!!!! I hope and pray that you get well soon! Yes that's fine your mother is fine dropping it off and she can leave the keys in the same compartment."*

I replied with, "*Thank you, I really appreciate it! I need all the prayer I can get. Thank you so much."*

My mom drove from Maryland to Reston, Virginia, came to the hospital, retrieved the key, returned the Turo, took an Uber back to the hospital, and stayed to ensure that I was receiving the right treatment. From then on, my experience and health began to improve. The nurses started checking in on me and administering my medicine on time. They answered my requests.

The next day, Monday, a specialist stopped by my hospital room to see how things were going and I could tell that she truly cared. She was the first person in the hospital to listen to and hear my concerns and empathize with me. She was genuine. Following her visit with me, she created a treatment plan for the hospital staff to follow.

Over the next couple of days while under her care, my health began to improve. She checked in another time, and adjusted things accordingly. In her care, between Monday and Wednesday, my pain diminished, and by Wednesday, May 16th, my pain had decreased enough for me to be discharged. Two days of proper care is all it took.

The doctor sent me home with prescriptions for medicine to continue treating myself at home. The following day, on the 17th, I visited her office for one more checkup in which she gave me the clearance to return to work.

And that is the story of the time I had a Sickle Cell crisis while living out of state.

Takeaways

Before we sign off, I want to address some of the lessons I learned through this crazy experience.

1. As stated before, preparing yourself for a potential medical emergency ahead of time goes a long way. If you have a medical condition and you are traveling or relocating, make it a point to find a physician, medical center, or hospital that is equipped to provide you with the best treatment. Your life could depend on it.
2. On a similar note, it helps to keep a record of past hospitalizations or paperwork related to your health. Hospital admittance and discharge always comes with some sort of documentation. Being able to provide this documentation can help accelerate your treatment. This is something I did not consider when I transitioned into adult care because I was accustomed to my mom and my Specialist handling all that stuff. I learned the hard way that supplying hospital staff with supporting evidence may help my case. Moving forward, I plan on keeping copies of my records within the files on my phone so that myself and my husband have access to them when necessary. If you have a Hematologist, Specialist, or Primary Care Physician that you see regularly, provide their contact info to the hospital staff so that the proper information regarding your care can be shared between both parties.
3. If you work in a medical facility, please empathize with your patients. This is especially important when it comes to people of color and people with Sickle Cell Disease. Use caution, but strive to be sensitive and understanding. Racial bias and disparities exist all throughout the medical field and patients of color are often mistreated for pain (Trawalter, 2020). Please make it a priority to become more aware of your biases and keep this in mind while tending to patients.

Outro

Alright! Thanks for tuning in to the “Feel My Pain” Podcast!

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K, thanks, love you, byeeee!