What I Didn't Understand Until I Did

I began my career in healthcare in the emergency department—first as a patient care technician in 2005, and then as a registered nurse after graduating from nursing school in 2006. I loved trauma, critical care, all of it. The pace, the intensity, the urgency—it made me feel alive. I truly believed I was one of the luckiest people in the world to make a living doing something I felt so deeply passionate about.

When most people think of the emergency department, they imagine trauma and life-threatening illness. In reality, those cases represent only a small fraction of what we see. Working in Albany, New York, a significant number of our patients were individuals experiencing sickle cell crisis. These patients were extraordinarily complex. Their desperation for relief from severe pain was often perceived as demanding or entitled. I remember thinking to myself: *Pain is awful—but don't they hear us doing CPR in the next room? Why don't they see that I'm triaging a baby in respiratory distress while they pace outside the room, waiting to yell at me again because their loved one is due for more pain medication?*

It was frustrating. At times, it made me angry. And slowly, it became far too easy to dismiss both their pain and their chronic disease.

In 2019, I made the decision to change specialties and began working in hematology. A significant portion of our patient population lives with sickle cell anemia. It was there—outside of crisis, outside of chaos—that I was forced to confront my own attitudes toward this population. And I was ashamed.

Now I was meeting patients who were not in the emergency department, but instead were trying to live as normal a life as possible while actively working to *avoid* hospitalization. While many people in their twenties are beginning their adult lives and discovering who they are, individuals living with sickle cell anemia are focused on survival—keeping lab appointments, adhering to complicated medication regimens, monitoring hydration, and remaining constantly vigilant. A minor illness is never just a minor illness. Rest alone is not enough. Dehydration, infection, or delayed care can quickly spiral into crisis.

They were remarkable people. And they deserved far better than I had ever offered them.

One moment in particular changed me forever. A young woman came into our clinic in crisis, and despite everything we could do, there was nothing more we could offer her outside of sending her to the emergency department. When I told her this, she begged me not to make her go. The fear in her eyes was unmistakable. I didn't need to ask why—I knew exactly what she had experienced there.

In our clinic, she had my undivided attention. I kept her warm. I did everything I could to make her comfortable. She knew she was in the care of someone who understood not only her pain, but the very real risk of ischemia, organ damage, and death. She knew her symptoms would not be dismissed.

I gave report directly to the emergency department staff, and eventually she agreed to go. I cried the entire drive home that night. I cried again in the shower. I was horrified—not by the system alone, but by my own past behavior within it.

I still understand how triage works. I still know how to prioritize patients in the emergency department—assessing who needs immediate intervention and who can safely wait. But I also understand now that in sickle cell crisis, pain *is is*chemia. Pain represents dying tissue. These symptoms are serious. They are life-threatening. And they should never be dismissed.

Most importantly, patients living with sickle cell disease deserve dignity.

To anyone I ever cared for without fully understanding the magnitude of your disease, I am truly sorry. What I once perceived as difficult behavior was, in reality, a cry for help—for relief, for survival, and for humane treatment.

You do not owe me forgiveness. My hope instead is that an emergency department nurse reads this and pauses long enough to examine their own biases. That this reflection sparks awareness. That awareness sparks compassion. And that compassion creates a cascade of change.

As New York State marks fifty years of newborn sickle cell screening, we should celebrate the lives saved through early detection—but also recommit ourselves to what must come next: care that is informed, equitable, and rooted in dignity for every patient living with sickle cell disease.