

Thermostat Queen

Hospitals have become my second home even though I hate the smell
While families moved from city to city in search of greener pastures
Mine moved in search of a cure
Herbalists have torn my flesh and decorated my skin with hideous scars
Religious houses have offered drinks of all sorts, grainy, slimy, tasteless and disgusting
They called it “herbs”
But my blood hasn’t changed
It’s still as sickle as the crescent moon

A number of middle-class citizens start their life hustle between the ages of 15 and 18
I was told mine started at 3, but I truly felt my first crisis at age 5
After that, every day was a hustle just to stay alive, until the day I lose
I’d be a liar if I told you I haven’t felt like a loser
But an unpredictable life is as normal to me as it is to every other Sickle Cell warrior

I was born to work-from-home, a phrase the pandemic has now popularized
But it had always been my norm
Because who wants to hire someone who needs frequent emergent times off work
My resume had it bolded up-top “**SCA Warrior**”
Because I don’t want to spend the next hour
Explaining the fragility of my existence without being perceived as seeking sympathy
Explaining why common rules of consistency cannot apply to me
Explaining why I don’t need anyone to recommend more prophets or disgusting drinks
I don’t want to spend time explaining how my now divorced parents knew better
But chose their love – for which I live to suffer the consequence

Some people think I'm attention-seeking
Who is going to tell them that my bank account is dry from all the attention?
Others are quick to offer advice as gifts
Who is going to tell them that the greatest gift to me is blood and money?
Have they donated any?
At the risk of sounding like a vampire or a ritualist
Don't give me advice. Give me blood. Send me money
Because my ship is sinking, and I know it
My friend died with 7% of blood left in her
Her last words to me were "I'm sorry, I lost"
Her loss put me into a crisis
Because stress is a trigger, and so is temperature

So, I'm in charge of the thermostat at my family house
When I say it is hot, then it is too hot
When I say it's cold, turn up the heat because it is bloody cold
It's the only time I feel empowered and in charge of something

The "thermostat Queen", they say at home
At least someone thinks I'm a Queen
My siblings could wear duvets or shorts and bikinis around the house for all I care
Because as "Queen of the thermostat", my comfort is considered as priority

But it's really the only time I feel in charge
Because even to my body, I feel like a weakling