LORA RUTH WOGU

SELF

I did not set out to advocate for people with sickle cell disease. My story actually begins where motherhood and my professional role as a Healthcare professional intersect. Most mothers of young children with special needs at some point feel a huge isolation. No one seems to understand what you are going through. Disability still carries a stigma in many communities, like it's bad luck, or punishment of some kind, something shameful. I had no idea what to do, where to find support within my community.

Now I see how this personal struggle created the conditions for me to find my purpose, because it made me more sensitive to disparities I encountered within my community, and experiences of others at work relating to disability, all the isolation and stigma. After the first time I met someone with sickle cell disease, I wanted to understand what it was? I had never heard of it before. Through my role working with patients, I met more people with this condition, and I was determined to learn everything I could about it.

 For one, why were they seeing haematologists for cancer? It turned out there just weren't doctors specialising in this disease, which is new in Ireland, and so, many people were ending up with two different doctors looking after them.

Motivated by my own experiences with medical stigma, eventually I started to work with doctors to bridge the experiences of the patients. My job was simply caring for others, not just about disabilities, but this illness came with so many more social complications that needed attention. There was and still is stigma in the African community regarding this disease, and stigma leads to a lot of isolation, because cultural and religious beliefs cause people to hide their condition. I wanted to raise more awareness and allow people to see that someone cares. I wanted to take them out of isolation, to share their stories, and to help them get proper support. I wanted to get our community to stop stigmatising the condition.

US

There is a huge lack of trust within the African community in relation to medicine and healthcare. Many believe in alternative or herbal therapies for most conditions, including Sickle Cell Disease.

The sad outcome of all this stigma is that the sufferers are then viewed as backwards or superstitious, not modern. But there are good reasons for their mistrust of the modern medical system, there are many documented stories of medical testing on Black people by white medical systems. During the slavery era in the US, for example, when Black peoples' bodies were used for the Tuskegee Syphilis Study, or the so-called father of gynaecology J. Marion Sims' experiments on enslaved pregnant Black women. There are recent examples, too. In many cases the resistance is mainly due to lack of knowledge, especially as these stories have circulated within the African communities.

That said, when parents don't know about the illness' genetic links, they might have a child who is born with the disease and dies. Stories circulate: were they cursed? Is God punishing them? Or people might assume it was AIDS, which is better known and also very stigmatised. And so, they remain enclosed in a culture of shame.

However, the more we advocated for people with this disease, the more I uncovered other disparities affecting the migrant community. My community is missing from participating in

research, clinical trials, health education and advocacy among others. Our fears and mistrust surrounding anything to do with modern healthcare limits our participation in studies, and it leads to avoiding health services, sometimes using herbal remedies even when we know we need stronger interventions. It also limits our ability to acknowledge mental health issues, so we don't get the support we need. I want to change that, primarily for people of African and Asian descent. I keep asking: how can we actively and visibly contribute to improving trust and access, so that when these policies are drafted, our experiences and needs can be considered?

This question motivated me to sit on a lot of committees, and then it was obvious: the healthcare system in Ireland is profoundly lacking in terms of diversity. But there is a lot we can do to help change that.

An important question remains: how do we convince Black people in Ireland now that they will not be exploited? How do we ensure that this is, in fact, true? Even when so many of the studies now are simply questionnaires and surveys, many Black people still don't want to share their experiences. The problem is a huge lack of trust, first and foremost, and then secondly, a lack of belief in drugs and medication. There's often the belief that the medication might cause more harm than good. ***The lack of trust must be addressed.***

NOW

Healing broken trust is not just about medicine, but about Black people feeling and actually being seen, heard, protected. This is not just about ticking a box. This is not just about inclusion or representation, but about mutual involvement. Healing broken trust is about acknowledging and shifting power, not just wielding the power to include.

And the time to do this is now. The population in Ireland is changing. We have an increasingly diverse population. It's about EVERYBODY now. Children born here call themselves Irish. They are citizens of this country. They need to grow up in a system that recognizes them as an integral part of the country, not an afterthought. We migrants who arrived here have adjusted, for better or worse. But our children have a different perspective: they need to be a part of the decisions and strategies that will govern their lives. The younger generation should feel they are home here, and that they have a say in the future of Ireland, regardless of race, colour, class or gender. After all, in another 30 years they will participate in running the country.