



Life as an Albino in Africa

Witch doctors target Tanzanians with albinism but sun is the biggest enemy.

By DANA HUGHES

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Like most middle-class 14-year-old girls in Tanzania, Joyce Charles enjoys hanging out with her friends, going to school and watching television. But she has albinism, a condition that leaves her without any pigmentation -- white skin, bleach-blond hair and pale blue eyes.

She sticks out in a crowd of her black peers, which is about more than just being different: It's increasingly dangerous.

In Tanzania, like most of sub-Saharan Africa, people with the hereditary condition are often thought of as having supernatural powers, which makes them a target.

At least 20 Tanzanians have been murdered this year alone, mutilated for their body parts, which are then sold on the black market by witch doctors. The estimated 170,000 albinos in Tanzania are on edge, feeling as if they are being hunted.

Joyce was almost a victim.

A few weeks ago on her way to school in Dar es Salaam, she was spotted by human poachers. "Two men passed by riding on a bicycle, and I heard them saying, 'When you take that lady, you are going to become rich,'" she says.

"After a few minutes a man standing beside me asked me if I knew the two men who were across the road. I told him no, and he told me to be aware of them since they were talking and pointing towards us."

Shaken, she ran home and stayed home from school that day.

"I feared because I have heard many times before that albinos have been killed," she says. "When I saw the two men pointing towards me, I feared that the same would happen to me."

Her mother, Yustina Mloka Charles, says that Joyce is no longer allowed to walk outside their neighborhood without an adult accompanying her. Charles's sister takes her to school.

"I didn't used to worry at all," Charles says. "But since the day my daughter was told, even if she runs, one day they will get hold of her, we are extremely careful."

Charles says the biggest challenge is not the threat of poachers but the everyday hurdles of parenting a child with albinism.

Although neither she nor her husband has the condition, both of their children do. Because albinism is caused by two recessive genes, it is seen in higher numbers in societies that are isolated or in countries where there is intermarriage. In many African countries, the rate of albinism is about 1 in 3,000, compared to roughly 1 in 17,000 in the United States.

Joyce has a 5-year-old brother, Peter, who, like most little boys, loves to run around and play outside in the hot African sun. But for Peter, an innocent game of soccer has lasting consequences. For people with albinism, the sun is the enemy, a hard concept for a rambunctious child to grasp.

"When I am around, I can make him stay in for a few minutes," his mother says.

"But I have a job, which makes me come back at home around four or five in the evenings. The house help has her own chores and thus cannot always keep watch of [Peter], who is extremely naughty. As a result he has some burns on his face."

Both children are supposed to wear long sleeves and hats whenever they go outside, but Charles says that, too, is almost impossible to enforce. Joyce, as she has gotten older, will sometimes refuse to wear long sleeves or a hat. And Peter is outright rebellious about it.

"I have bought him lots of hats, but you always have to insist that he wears his hat," she says. "At times he does not feel like wearing it, and you will see him running off without it. He actually doesn't like to wear the hat; you have to force him to do so."

In Tanzania, sunscreen is extremely expensive, even for a middle-class family like the Charleses. In an effort to acknowledge albinism in the country, the ministry of health provides some sunscreen to people who register with the Tanzanian Albino Society, a nonprofit advocacy group. But Charles says more needs to be done.

"The government promises to bring us lotions that would help the kids protect their skin and, when they bring them, they are not enough and people end up not getting them," she says.

She says her children are well-liked and have not faced discrimination in the neighborhood or at school. But they sometimes forget that there are many "normal" children's activities in Tanzania that they cannot do, she says. And she worries about the increasing violence against people with albinism, a term rooted in the latin word meaning "white."

"Sometimes I wish my kids could go to a boarding school where they could be inside mostly and not have to deal with these daily hurdles," she says.

If Peter continues his refusal to wear any protective sun gear, there is a good chance that he will end up at the Ocean Road Institute for Cancer in Dar es Salaam, a specialized cancer hospital that treats albinos for their biggest killer: skin cancer.

There are no official statistics, but Samwel Mluge, the secretary general of the Tanzanian Albino Society, whose offices are on the hospital's premises, says that many people with albinism end up there. It's especially true with the elderly and people from rural communities, where family members are expected to work outside on the farms.

One woman from the Mwanza province near Lake Victoria, where many of the killings have taken place, has been getting radiation for skin cancer she discovered in March.

Although she is only 36, her rubbery skin envisages an age twice that. Her face is full of burns and sores that she must tend with a handkerchief every few minutes. She doesn't want to give her name, but claims that she doesn't face discrimination because of her albinism, which Mluge believes is denial.

"When you are born an albino in a family or a neighborhood, the major problem, especially here in Tanzania, is stigmatization," Mluge says. In rural communities especially, "they do not expose their problems because of fear. They think if they expose these problems, they'll be rejected by their families."

In addition to cancer, poor vision is another health issue facing people with albinism.

Nearly all of them experience low vision, making it difficult to do well in school because students often can't read the chalkboard.

At 5, little Peter Charles already has trouble focusing; his blue eyes dart back and forth before looking directly at something. Joyce, 14, wears thick glasses, something most Tanzanians can't afford. As a result, many children simply drop out of school, perpetuating a cycle of poverty.

"Sometimes the teachers do not have the knowledge on how to handle pupils with albinism in the classrooms," Mluge says. "So you do not have any assistance."

At the Tanzania Albino Society, Mluge and his colleagues work with parents of kids with albinism to get them to take a more active role in their children's schooling, forcing teachers to take their child's albinism into account when teaching, as well as encouraging parents to get glasses for their children. "You need to have self-determination in order to learn better," he says.

In Dar es Salaam, discrimination is beginning to wane. There are more children like Peter and Joyce, who attend school and are part of their community, than ever before. This

year, Tanzanian President Jakaya Kikwete appointed the country's first minister for albinism, and the government has ordered a crackdown on witch doctors who target the community.

But stigmatization, poverty and danger are still the norm in the rest of the country. Parents routinely hide their children instead of sending them to school, and beliefs in their magical powers are still prevalent. Just last week, a man was murdered in the Mwanza province, his body parts allegedly given to witch doctors, for a handsome fee.

Mluge says he would like the government to begin classifying albinism as a disability to give those living with the condition more education and a better chance at success. The Tanzanian Albino Society provides hats, sunglasses and education about albinism to those who register with the organization. But with an operating budget of \$15,000 annually, the organization can only do so much, Mluge says.

"We need a permanent donor to provide money for activities for people who are coming into the hospital, to educate people living with albinism," Mluge says.

He also advocates more education for the rest of the country about albinism, to try to end the belief that people have magical powers. He says education is the key to ending what he calls "widespread stigmatization" against the community.

Joyce Charles represents what Mluge hopes will be the future: confident, smart and integrated into society.

Joyce says she plans to be a doctor when she grows up, and sees no reason why her albinism should stop her. "I would like to help all kinds of people," she says, "be they albinos or not."

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