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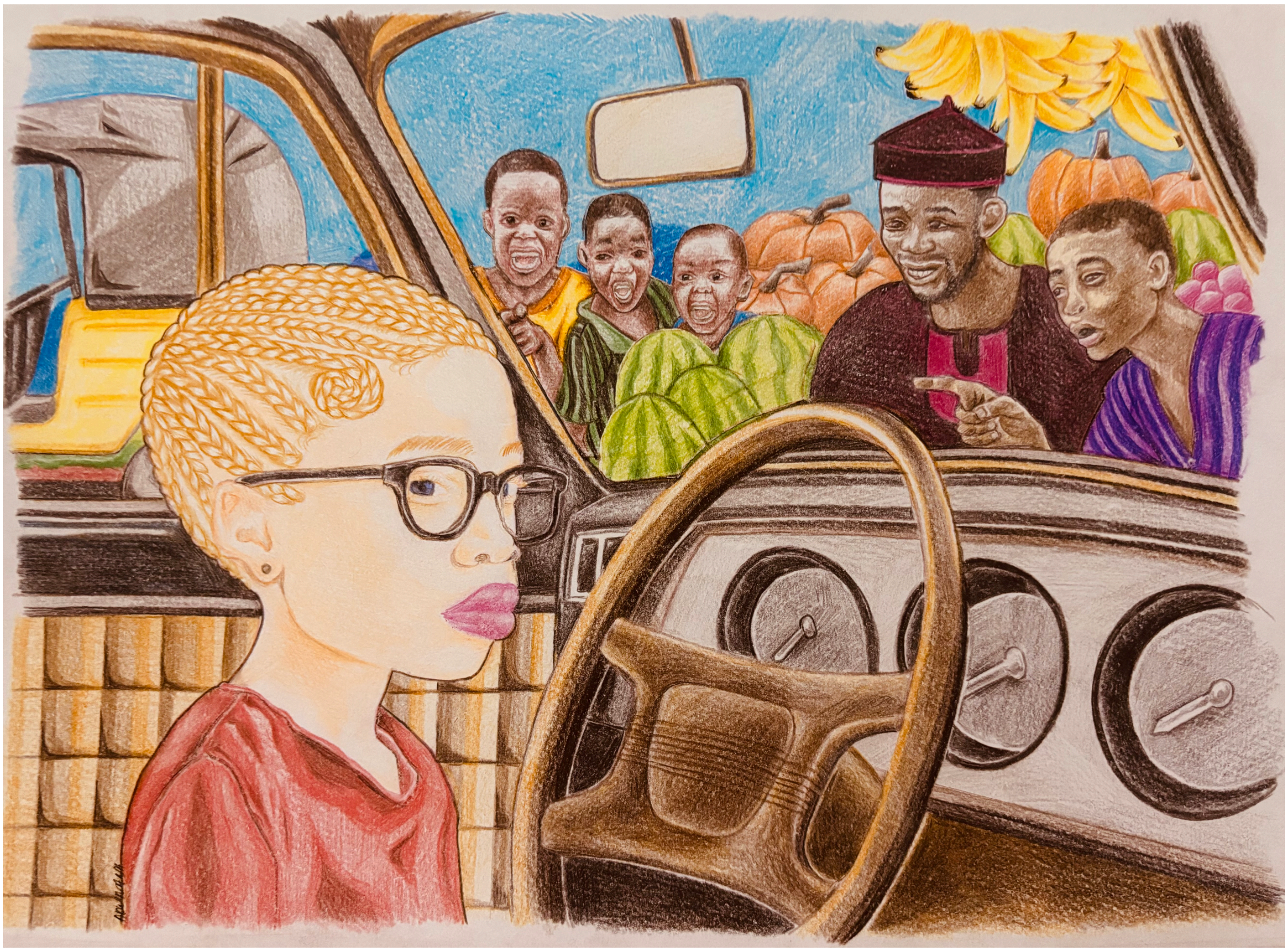
IKPONWOSA "I.K." ERO

This is war

Fighting back against the violence faced by people with albinism



"Market Days", by Athenkosi Kwinana

Dear Debriefers,

Growing up with albinism in Nigeria in the 1980s and 1990s, my own childhood was harsh in many ways. I encountered widespread stigma and discrimination.

But when I started advocacy, I found things could be much worse. I had heard about ritualists allegedly targeting people with albinism. Surely, I thought to myself, these cases are rare and sporadic, or limited to specific cou

Subscribe

I was wrong. Cases of murder or mutilations were reported acros countries. In my work I talked with both the victims and the perpetrators to find out why these were happening.

Due, in part, to the advocacy in the last two decades, reported attacks appear to be trending downwards although the fact that they continue is highly disturbing.

This article is the story of my own childhood and about the horrific violence faced by people with albinism; and how we as a community are fighting back.

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Gratitude to God

At my traditional naming ceremony as a baby, guests and relatives queried how and why I had albinism, and my parents quarrelled about where the condition came from.

Thankfully they settled on my name, *Ikponwosa,* which expresses gratitude to God in the Edo language of Nigeria. I have since met several people with albinism with names such as *Shida* or *Matatizo dunia*, Swahili for problem and global challenge, respectively.

My parents were teachers and by the time I was in kindergarten they had, with some research, overcome a lot of their qualms about albinism. Luckily it did not break up their marriage as it does to many.

At kindergarten another child chased me relentlessly to hit me on the head with his closed fists, rocks or anything he could find. I would hide to get away, but I was unsuccessful, mostly due to my low vision. My parents and the school would have to intervene several times before I got respite.

The different dimensions of albinism

Albinism is a condition that results in a lack of pigmentation in the skin, hair and eyes. If left unchecked, there is a high vulnerability to sunburn and skin cancer. And the condition often causes a vision impairment that lead many to meet the definition of "legally blind" in their countries.

The type I have is the most iconic form of albinism, affecting all of the hair, eyes and skin. Scientifically this is referred to as oculocutaneous ("OCA") albinism. Persons with albinism in general, and the OCA form in particular are often very different in appearance from their family members and their ethnic group.

In a place like Nigeria, where the population is generally homogenous, black people with albinism like me really stand out. To understand these experiences, we need an intersectional lens to take into account the several impairments, as well as role of the role coloring and appearance in the discrimination against people with albinism.

"Don't mind them"

By age seven, I decided to opt out of opportunities to go out of my home. The negative attention was far too much. Children would chant following me, particularly in the open market and in town. They often sang a popular but unflattering Yoruba song, "*aafin oriran l'osan oh*…", about the vision impairment that often comes with albinism.

Adults would comment about my albinism from car windows, point with their children or discuss erroneous facts about albinism in my presence. The more educated adults would refer to me as an "Unfortunate European" which was invariably followed by laughter. Some of my own Edo-speaking relatives would call me, *ebo n'ehui,* meaning "the white person of the black race."

On my mother's trips to the open market – often on the way back from the many eye appointments she took me to – she would leave me in the car with the window cracked open to spare me the chants.

But it didn't always help. Children would soon gather at the window and sing, discussing my appearance and laughing. I would cry silently, unsure of why I couldn't ignore the situation.

Family members' show of support in these instances was often the phrase "don't mind them." It was an immense consolation because I knew that to some extent they understood. But I could never live out their advice completely.

My own reflection

Through the glass window of my mother's car, I saw myself in those children. As a child constantly surrounded by melanated people whose genes and culture I shared, I always assumed I belonged and that I was one of them. I wanted to roam free and play, but from their own vantage point, they saw something else.

My own reflection in the mirror and my mom's car window rudely reminded me that I was different and why I was being treated differently. In the African context, where belonging is both paramount and communal, the African child with albinism is forced, at an early age, to contend with their place in the culture and their sense of belonging.

Simply wearing traditional clothes on our pale African skin often provoked laughter, how much more trying to become a local chief or a respected member of the community?

Shame

When I was at primary school, my desk was placed a few feet away from the chalkboard, as a result of my mother's dogged advocacy. My mother prepared me to advocate for myself at the boarding school I went to for secondary education. But I was too ashamed to ask.

By then I felt that my albinism was a bad thing and that it was my fault. I had to do all in my power to avoid any unnecessary attention.

So I struck a deal with a friend. She wrote down the notes and exam questions on the chalkboard, and I did her assignments and exams. I managed to cope with the tenuous deal, although she always got carried away at her own joy in mathematics, that she forgot to provide the questions to me.

I finished secondary school in Canada after my family moved. I had enormous support, but my shame remained. I was on the margins once again. Being black with albinism was a huge surprise to many in my school and community. Some rather loud peers called me "white n****r".

I had to learn how to pretend I didn't hear the comments.

Power and powerlessness

As I finished university, my shame faded. As well as intervention from my family, the emergence of the internet was pivotal in understanding my condition and in joining a global community of people who looked like me.

The American albinism community ran a web forum, where a lot of my experiences and thoughts about albinism were validated, and there was advice on thriving.

After studying the basics of human rights, I realized that no other person had a right to question my existence simply because my physical appearance was relatively rare. I rejected the powerlessness often attributed to being in an “odd” minority group.

It is this general linking of power and powerlessness to what is considered “normal” or “not normal” that causes so much harm. I faced bullying and abuse, but as I found out when I learned about the global situation, many people with albinism face worse.

Hate crimes and humanitarian crisis

I first learned in 2008 about ritualists in Tanzania interested in the body parts of people with albinism and their supposed market value. Surely, I thought to myself, these cases are rare and sporadic, and it was only in Tanzania.

But I was wrong. In 2009, when reports of attacks were so alarming, a Red Cross report described it as a “humanitarian crisis.” A few years later, as scores of cases were reported across other countries in the region, the UN Expert on extrajudicial killings recommended that the cases be treated as “hate crimes.” In addition to murder there were cases of mutilation, trafficking, and grave exhumations for the sake of stealing remains of people with albinism and to sell them.

The motivation – based on widespread but wrong beliefs – is that the bodies of people with albinism have supernatural powers. Allegedly these powers can help to win elections, promotions at work, or induce more gold in mining and more fish in the fishing industry.

And there is a reported commercialisation of these practices. No physical markets have been found but several people have been caught transporting body parts or have alleged that they were promised amounts equivalent to thousands of dollars.

When will this end?

Over the last fifteen years, Under the Same Sun has tracked over seven hundred attacks on people with albinism from 31 countries, of which 242 were murders. There is a downward trend in attacks, but they continue. And there have been many horrific attacks in the last year alone.

One of the most horrific attacks was in Tanzania. In May 2024, baby Asimwe was killed. She was only two years old. Her remains were found, mutilated. Among those arrested were her father and a priest.

And less than two weeks ago, a 25-year-old man with albinism was murdered in Zambia. His remains were found two days later mutilated and missing body parts. On hearing this, I was devastated. When will this end?

Currently, there is direct intervention in Zambia by a few civil society and government officials, including in the area of public education. But clearly this is not enough. I feel exasperated at law enforcement because I believe they should immediately implement more protection measures. And the government should urgently put a national action plan in place.

Until these concrete measures are successfully implemented, I, like others in this movement, have to brace ourselves and keep up the fight with all our might.

This is war

We are fighting against extreme forms of exclusion and discrimination. “War” is the most apt description where one is being hunted and killed simply for having the genetic condition of albinism.

I understand that this is strong language, but I see myself as a frontline soldier. The main weapons on our side of this unconventional warfare are the human rights frameworks, combined with strategic advocacy, doggedness, and integrity.

We are battling against the caricature of people with albinism in your movies. We are battling against the myths that we do not die but disappear, that sexual relations with a person with albinism can cure HIV/AIDs. And, most horrific of all, the myth that our body parts can generate wealth and good luck when used in rituals related to so-called witchcraft.

We have won victories, but the war is not over.

Understanding the causes of violence

One of the weapons I have used in the war is amassing and using data strategically. From 2015 to 2021, I served as the inaugural UN Independent Expert on the enjoyment of human rights by persons with albinism. In this role, I pored over cases of attacks, met victims, and survivors, some of whom are missing limbs. I also met some alleged and convicted perpetrators in prison.

I discovered some similarities in the contributing factors of attacks across impacted countries, including some of the misbeliefs discussed above. However, there are also country-specific factors distinguishing each national situation.

Potential economic gain

Attacks are often driven by the alleged potential market value of persons with albinism. This appears to be a factor shared across all impacted countries.

In Malawi, perpetrators were caught with body parts of a person with albinism after they had not found where to sell them. In South Africa a traditional healer called the police after someone tried to sell body parts to him.

In Madagascar there has been an outbreak in cases of attacks over the past few years. Poverty, aggravated by climate change, appears to have fuelled the attacks.

However, some of the poorest countries in the Africa region – such as Somalia – have almost no reported attacks. It shows that there are other factors to consider.

Cross-border criminals

One theory is that there are a few actors behind these acts who tend to move around internationally.

The main evidence for this is the tendency for cases to trend in opposite directions in countries which share a border. For example, cases go up or down in Malawi in the opposite direction to the trend in neighbouring Tanzania or Mozambique.

And shared elements are eerily similar across several countries. A chain of coercion runs down through influential people – like businesspeople or religious leaders – to economically vulnerable people who then pressure family members. Often the victim is a child from a rural area.

This suggests that strategic intelligence gathering, and cross-border cooperation could seriously mitigate and put an end to these crimes. The fact that cases continue is an indictment of the failure of all affected governments.

Imitation and dangerous myths

Cases of attacks are also reported in countries without shared borders. Madagascar appears to have begun facing frequent attacks nearly a decade after cases appeared in Tanzania and neighbouring countries.

Dangerous myths and misbeliefs probably facilitated the imitation process. Care must always be taken to dispel myths about albinism and that articles reporting the money-for-body-parts aspect of this situation must be clearly countered in the same article.

It is therefore proper for me to underscore that the body parts of persons with albinism have no financial value and are not supernaturally efficacious. Anyone who plans to act on these false beliefs risks criminality.

Propagating these myths about albinism may also soon be a crime in some countries. In South Africa for example such protection is being incorporated into a draft bill on hate-speech.

Increased attention and the road ahead

For a long time these practices received scant attention. Part of my work as UN expert led to a ground-breaking resolution on accusations of witchcraft and ritual attacks. It was followed by the Pan African Parliament adopting guidelines. These are milestones to demystify albinism and humanize the condition.

However, there is a seemingly slow progress in putting concrete measures into place or following the African Union Plan of Action on Albinism. The road ahead is long but it is not lacking in directions.

The killing of Asimwe in Tanzania last year was a battle we lost. But the fact there have been no reported cases in Tanzania up to writing this article at the start of 2025 shows there is a tentative victory, especially when compared with the frequency of cases a decade before.

A huge growth in community

At the start of the twenty-first century there were around thirty civil society groups representing people with albinism worldwide, including those led by people with albinism ourselves. Today, there are over two hundred worldwide with about ninety percent of these from Africa alone.

This is no small feat. It is a testament to how human rights frameworks empower those most affected by violations to use their voices to advocate for positive change.

These groups have been central to the achievements of policy work. And they open the door to a new future for persons with albinism born globally, and in Africa in particular. There is a future of a truer belonging.

Alone in the car

I now look back to those times in the car, where I was consumed with the pain of exclusion due to my albinism.

Looking back, I now understand it as preparation. The scars from those experiences were a source of motivation for me to fight this good fight.

This is not to condone or call for painful experiences. No. No one needs them to accomplish good things. However, if painful experiences come anyway, it can be helpful to see them as a training ground for our yet unknown mission. I hope that we can hold onto the strong possibility that negative experiences may one day result in good – both for ourselves and for a multitude of others across around the world.

Indeed, that is what I would have liked to tell my younger self, locked in my Mom's car on those hot market days. The mockery and fear I was encountering were shaping me for battle. They were forming the empathy and passion needed to fight with resilience. They were rocks sharpening a sword.

With you in mission and hope,

IK

Outro

Follow IK Ero on Linkedin. See also the website of Africa Albinism Network.

For more on Athenkosi's art, see her Linktree or follow on Instagram.

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