Stories about Albinism in Malawi: an 'intruder' in my village

Lund, P. (Editor), Nyirenda, M.

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AN "INTRUDER" IN MY VILLAGE

Michael Sydney Nyirenda, journalist, tells the story of how he first heard about albinism as a young boy in his village in Malawi, relating the myths and beliefs about albinism in his community. Then he met lan Desmond Simbota, a young man with albinism. They became firm friends and colleagues.

It was a beautiful Saturday morning around 9 o'clock. I was coming back from the maize garden with my hoe resting on my shoulder. I was hungry and tired and I needed at least a one hour rest at home, before taking a three hour long journey on foot to Hoho Community Day Secondary School for an inter-secondary school football match later that afternoon.



A maize field in rural Malawi, with Lake Malawi in the distance

As usual, it was almost inevitable to prevent meeting the people, especially women in the village because the way to the maize garden passed through the people's huts (compound).

But that morning it was different. I did not meet any woman or any man as was the case but a nine year old boy Vitumbiko Kumwenda.

He was the first person to meet with that morning and it seemed he had something terrible to tell. He ran after me while calling my name: "Syd" instead of "Sydney" which is my full middle name.

I reluctantly turned to him and judging by his facial expression, I could tell that Vitumbiko had a strange story to tell.

He quickly broke the news to me: "Alongosi a Tereza wawerako kuchipatala na mwana mutuwa nge mzungu."

(My sister Tereza is back from the hospital with a white baby like a European.)



A baby with albinism born to a black mother

I was deeply shocked and frightened.

"A white baby? Are you sure?" I asked him.

"Yes," he answered me with confidence and then lowered his voice, "But please don't tell anybody about this." he warned me and quickly disappeared in the kitchen.

He left me almost dead for a moment with my head more full of questions than answers.

"White baby? How come? Tereza is black, so is Mumba her husband; so how come that they have a white baby?" I asked myself all these questions because it was my first time since I was born to hear a black couple having a "white baby".

"This is abomination" I thought.

And in no time, I recalled what my brother told me that dead people do come back to life by being born again as 'Ghosts' but in the form of 'white babies'. And when they become old he told me they do not die but disappear. He also told me that if you see a "baby ghost" with your naked eyes, you will disappear together with it when it becomes old.

When I remembered this, fear gripped me and I quickly left the place without looking back for fear of my eyes bumping into a white baby.

Eventually I resolved to do two things:

- 1. Not to pass through that compound again when going to the garden for fear of seeing the baby
- 2. To find out more about the white baby from anyone in the village especially the parents.

However, days accumulated into weeks and weeks into months without meeting anyone interested in giving me more information about the 'white' baby.

Many people including my own parents could ignore my questions and quickly switch to another subject or else stop me directly from talking about the baby.

And gradually I began losing interest in knowing more about the white baby.

After about three months I started using the same way to the maize garden because the couple could always keep the baby indoors so it was almost impossible for anyone to see her.

Unexpectedly I saw the baby in the arms of her mother when I was passing by the compound one day.

Fear engulfed me. I will disappear one day when the baby becomes old, I thought.

But I did not tell anyone that I had seen the baby; not even my parents.

I could just fearfully think about it again and again until the family left the village secretly for the husband's village.

Later we heard that the family was forced by the village elders to leave the village apparently because they (elders) were suspicious of the 'white baby', believing that something superstitious might have happened to the family.

They connected the birth of the baby to the strange tradition the couple followed when marrying, because they followed matrilineal system instead of patrilineal system which is commonly practiced by people from the Northern Region of Malawi.

People suspected that both parents were bewitched.

MEETING IAN DESMOND SIMBOTA



Fast forward to 2009, I met Ian Desmond Simbota (left, sitting next to me). I never saw a person living with albinism until I met Ian at Malawi Broadcasting Corporation (MBC). I could understand albinism at this time; and therefore becoming friends was not a problem. We had and we will still have something in common. We do produce and present programmes together e.g. youth link. We write scripts for stories in action which is a radio play air on Radio 2 FM. etc.

However, five years with Ian has opened my eyes wide to see the underground challenges people living with albinism are facing in Malawi. I have come to realize that:

- People living with albinism are still strangers in a society full of people with black skin. Therefore stigma and discrimination is common even at work/school. Sometimes name calling e.g. Namphweri
- Media has not done enough to change the mindset of people especially in rural areas, who have different beliefs about people living with albinism, and that is why I developed an interest as a journalist to specialise myself in reporting stories about albinism
- Government has not taken any notable step/ initiative specifically to help people living with albinism other than a disability as a whole e.g. providing sunscreen lotion, long sleeved clothes, hats, creating a good learning environment for learner living with albinism

MY WISH

Finally it is my hope that everyone should take a responsibility to make sure that people living with albinism in the country (Malawi) and the entire world are accepted and enjoy their rights and freedom just like everybody else regardless of colour.

Together we can

Author: Michael Sydney Nyirenda, Journalist.

THE END