

ALBINISM IN AFRICA: INTERVIEW WITH STÉPHANE EBONGUE KOUBE

How do you define albinism in Africa?

Apart from the scientific definition that connects it to rarity, melanin and skin tissue, in Africa one must include prejudices in the definition of albinism. There are many prejudices. For example, people believe that albinos are immortal, have the ability to see at night, that parts of their body are useful for magical potions. So it is one thing to be an albino and another still to be an albino in Africa due to these types of prejudices.



The perception also varies in another way; those that believe strongly in the powers of albinos do not have albinos in their family or close to them. Once people have an albino close to them they realize that these perceptions are completely false. It is those that see albinos from far away or have never even seen an albino, who will be most susceptible to false beliefs. For example, my wife used to have a different perception of albinos, thought of them as strange people, but once we met and loved one another she no longer gave the issue any thought. She now sees albinos like any other person with their defects and merits.

In your opinion have albinos in African society always been perceived as people to fear, to isolate or use in

rituals?

Africa is made up for 54 countries so the situation is not exactly the same everywhere. There are some places where albinos are considered like a gift from the Gods. In other places albinos are considered a curse.

Albinos have a different value depending on where they are living. In both cases there is always this idea that the parts of the body of albinos or the life of an albino can be useful for society, but I must emphasize that depending on where they are they are not treated exactly the same way.

This has always been the case because it is a problem connected to culture, and a bit to animism. Animism in Africa is a belief that exists regardless of social strata, regardless of education; it asserts that all living things have a spirit (water, wind, trees), all things that exist. And this mode of thinking makes it such that death does not exist, death is a form of life and those that are deceased must live somewhere and serve as a channel between God and the living. This belief considers all events in African society, such as the birth of an albino child or twins, abundant rain, the eruption of a volcano, barren women, in connection with animism and relationships between the world of the living and the ancestors.

What are the main challenges of being born with albinism in Africa?

Apart from the clinical problems, the main two being myopia and fragile skin that burns easily in the sun, there are social problems. Albinos are sometimes not even accepted in their own families, they have difficulty finding work, and they are killed on a daily basis. The other aspect of being an albino is that they are unable to attend school because albinism is considered a handicap. Many leave school for the street because of poor vision, they sometimes have such weak eyesight that they cannot see the blackboard so they abandon school and end up on the streets becoming either prostitutes or beggars.

In some countries it is believed that to give an albino offering, for example if one has a project or a person wants a visa to go to the West, will ensure that one's needs will be fulfilled or problem will be resolved. The social consequence is that albinos are confined to being beggars, they do not go to school and they are engaged in the prostitution ring.

If an albino is sacrificed for a certain purpose and that purpose is not achieved, are there reprisals against albinos?

No, there are no reprisals. On the contrary, it is believed that perhaps the offering was not substantial enough or not properly made. The fact is that those who give the offerings are absolutely certain that these sacrifices will give results, so when the results are not seen the person who made the offering feels guilty for not using the sacrifice properly. To give another example, on the eve of Election Day politicians will make human sacrifices to win. When a politician has not won a government seat he thinks that maybe his witchdoctor was not capable or strong enough to properly use the sacrifice - the next time he turns to a stronger witchdoctor. When you have elections only two outcomes are possible, someone wins and someone loses, the winner had a stronger witchdoctor and the loser will turn to a stronger witchdoctor the next time. Football matches are also occasions for which albinos are murdered. Albinos can be sacrificed to go as far as possible in the competition. Again, when a team loses they believe that the witchdoctor was not skilled enough. Football teams can be accompanied by the so called "conseiller psychologique" (psychological counselors). They have nothing to do with the sport and if you investigate you find that they are witchdoctors giving advice of another nature to the team, recommending what to do from a metaphysical and magical point of view to win the competition or at least to get as far as possible in it. If one was not successful, the next time you take another and so the cycle perpetuates itself.

And if an albino refuses to accept a gift?

An albino cannot refuse. The problem is that he is poor, and has no other choice. Since an albino cannot work out in the field due to the fragility of his/her skin and does not go to school, sometimes it becomes convenient for an albino to accept a "ritualistic gift" because it is easy money. Albinos receive ritualistic gifts in the eve of elections and in some cases are enrolled in the army as human amulets. In some countries military heads believe that having an albino backing them will keep them safe. The consequences of this can then be seen, an albino that is a policeman will surely see a dramatic effect on his skin from exposure to the sun, which will finally develop into fatal skin cancer. It has always been this way; they consider that albinos are gifts, sources of protection: a politician who wants to win elections, a national football team that wants to win a competition that will give glory to the entire nation, a military head who wants to become invisible or the power to defeat or have to become invulnerable to bullet. At times, a woman will want to seduce the rebellious heart of a man who does not return her affections, so she asks for albino hair to mix into a love potion - the minimum. Sometimes it is believed that when fishermen weave the hair of an albino into their nets, it brings an abundance of fish, but this is still the minimum, hair, nails etc. However, to win the elections

you need an albino heart, to prevent a natural catastrophe you need the head, the body, the entire albino. It is believed that only the blood of one or more albinos could placate the God following the eruption of the volcano. And so these things are not at the same level.

Among albinos themselves, is there this same belief that they have special powers?

One that is used to begging ends up believing it. In fact for them it even becomes a source of income, so he/she says to himself that yes, he/she has a power... They begin to believe they have this power because at times they do not have a choice; it becomes a source of gain.

That said, albinos themselves do not profit from the black market that thrives off of them, it is not like I give you my hand and you give me a million dollars. This black market of limbs, organs etc. profits other people and organizations. The process is that they stop you at night, they attack you, they hack off whatever they want or they kill you and remove whatever they want. The albino never profits in this situation. Instead, the gain comes from if someone gives me money for a tuft of hair, if I go to bed with someone, these types of small things that profit them personally.

How is discrimination against albinos linked to religion?

It is not linked to religion, but more so to traditions. Religion is a very recent phenomenon with respect to discrimination, which has always existed against albinos. In my opinion, religion is more recent as it arrived with colonization. Instead, the subject of albinos existed from when Africa began to exist, so we cannot connect the two. The problem is cultural and found in the traditions of Africa.

And the witchdoctor is a figure of tradition and ritual?

Yes, when we speak about the witchdoctor we need to differentiate between the witchdoctor and the shaman. The apprenticeship is the same; they have the same power, which is neither positive nor negative. Power is power, it just depends on how one decides to use it. On one hand there are those that heal, this is called traditional medicine, they do not send for albinos to be killed. Though they are different, they use the same power and have the same secrets. On the other hand is a witchdoctor who uses his power for profit and negative ends, distinguishing the two figures.

Is it worse to be born with albinism in cities or in rural areas?

Beliefs are the same everywhere. Albinos are marginalized in these societies regardless of the place, be it in the city or in rural areas. However, perhaps in rural areas the situation is a bit better because consumerism has not yet taken over. In cities persecution may be more widespread; somehow it is easier to be attacked because the poverty there is harsher. Women who want to marry, politicians that want to be elected, football players that want to win competitions are more numerous in cities than in villages.

Albinos are always running the huge risk of being killed, but they cannot simply decide to leave one area for another. Leaving is not a simple or even feasible option for most; after all, one has to eat everyday. For those who do not have enough to eat everyday how can they possibly think of buying a ticket and leaving the country? To add to this, many of them are illiterate because of the challenges to attend school, so this idea of going away may not even occur to them. They could possibly relocate, but a social cage forms around them and perpetuates their situation.

Those that are caught in a prostitution ring, born into poverty, into the life of a beggar and live in these same areas stay there and continue to live this way because nobody says anything. I met a girl that has oral cancer, all her lips are ridden with tumors, but she is still limited to begging, even in this case the state does nothing. Her husband threw her out, she has two kids and her family does not want her. Without the money to get treatment she does not have any other chance than begging.

Do you think organized crime is involved in the disappearances and trafficking of organs?

I do not think organized crime is so much involved. Trafficking of organs is fed by traditional beliefs, rituals and powers. However, organized crime involvement in the disappearing of albinos and trafficking of organs does not have to be underestimated.

Do the immigrants living abroad, but coming from African countries where persecution of albinos exists lose this negative perception?

Yes their perception changes, but this is due to the prevalent mass culture, contrary to that of their country of origin. Those with a negative perception become the minority and so they start to see things differently. Here in Italy I was in a group of three men when we were stopped by the police, the other two were asked to show their documents, while I was not. This has happened to me several times.

Are families that include a family member with albinism discriminated against? And are they at a certain point forced to "take advantage" of albino children?

They are discriminated against in the sense that sometimes the albino is thought of as a curse, but it is the

albino himself or herself who is subjected to the worst discrimination. In terms of taking advantage, it can happen that poor families count on their albinos children for survival.

Some parents with an albino child born to them have few options, either they kill the child themselves to have him/her disappear immediately or sell him/her to whoever wants. In this way yes, the families take advantage of the situation.

Is there some kind of estimate of how many albinos are killed per year?

No, in my opinion, there is no reliable estimate because of the nature of the killings and since many cases are not reported. Some families also fear reprisals so they do not report murders. In addition, a family that decides to kill its own albino child will never report this.

Are there legal repercussions to encouraging or engaging in the persecution of people with albinism?

Legal norms are generic, but the state claims that it cannot put a policeman behind each citizen. These incidents happen at night so again we turn to sensitization because by night there is no security for albinos or non-albinos, but the problem is that violence against albinos is admired. If people understood that it does not serve any function to kill albinos, things could change. There is even this belief that those who have HIV/AIDS and go to bed with an albino woman will be cured. As a result, 52% of female albinos are infected with HIV/AIDS. So, to inform people that going to bed with an albino woman does not cure any disease, it only infects the victim, could possibly help change the situation.

Are there organizations that collect and take care of the albino children that families do not want?

Yes, there are some people or families that gather together these unwanted children or people. In Cameroon there is an organization like this, in Tanzania the state had a creative solution where they grouped together and closed off all albinos on an island called Ukerewe.

Do you think albinism is linked to the fear of whoever is different that many societies have often harbored? Albinism is a genetic complication present in all of the animal kingdom, there are even albino plants. But the prejudices are linked, I would not say to fear, but to the notion of the different. To somehow vent and avoid the implosion of society they invent these prejudices to be able to take it out on someone else, a group that is weaker, a minority. It is a social mechanism to regulate the perpetuity of society somehow. It is the fear of what is different that we see everywhere, in all human societies.

Can you tell us about the creation of albino communities to escape discrimination, kidnappings and killings?

Let us go back to the island of Ukerewe, which I believe is a unique case. It was quite an original solution to enclose all the albinos on this island to protect them from further attacks. Very often albinos group themselves in associations to resist prejudices, but more than anything else to help one another out because they do not receive any help especially in term of medical aid. Albinos form these associations to face problems together, for instance sunscreen and sunglasses are distributed for free to all the members of the association.

Do you think the confinement of albinos to certain areas could lead to the formation of a minority group?

Yes, of course the risk of ghettoisation or of the creation of a minority is present. Even the creation of schools for albinos is a form of creating or reinforcing a minority. This is why I think that the method in dispute should not be to confine albinos, but to raise awareness. We must speak to people, explain to them that albinos do not have these powers that they think they do, go into schools and teach children about albinism. In particular we should work on positive exposure, asking those albinos that have had some success to speak out about their experience. For example an albino that is a minister can speak to other albinos who are beggars and tell them that their position in life is not to beg. This could give a sense of esteem to other albinos, showing that we are not just beggars and we should not be beggars. We need to get educated because where there is a will there is a way to make strides in society.

Do you think albinos will be able to integrate if societies are able to accept and protect them?

If we do something, if we start to sensitize people, then yes because the cultural problems do not change from day to day. Time is needed, dialogue is needed, and a vast amount of awareness is needed. Concrete actions are needed from the states to consider albinos like any other citizen and to give them tools to succeed. For example, several times at school I had to consult a blank page because a font size of 9 or 10 made it impossible for me to read. I was at a disadvantage not because I was not able to compete, but because I was not given access to the competition. In my opinion states need to do something about this. Positive discrimination does not interest me. I want to see changes such that if an albino cannot read the documents given to him or her, the text is enlarged to size 14. However, states do not do this. In the case of sunscreen and medical treatment, states need to understand that looking after an albino's skin is not an easy task. Here in Italy, albinism is considered a rare disease and sunscreen is distributed by the public health

system, it should be the same everywhere. This will facilitate and favor the integration of albinos. By being exposed to an albino journalist, minister, lawyer, doctor, others will begin to understand that the beliefs they held are wrong. As I stand right now, it would not occur to anyone that I need loose change to survive. This is how people will begin to see that albinos are not burdens to society, but normal people with their own set of problems.

Awareness in my opinion is the most important issue, but there are problems in the field where we need to intervene. For example, I am involved in a project at the moment with the NGO A child with a future because it is time for concrete solutions. It is not enough anymore to simply state that albinos are being killed. In the meantime they continue to die, do not attend school, and have fatal skin cancer. In my opinion we need to raise awareness, but also do something on the ground. Kids need to go to school and receive medical treatment □ these are issues we should focus on. This is why I did not want to focus on my story. I want to help those that are left in Africa. They are the focus now.

About Stéphane Ebongue Koube:

I was born in Cameroon and I am an albino. I ran away from my country because I was persecuted by men who wanted my organs. They wanted to use them for talismans and magic potions. I graduated and now I work as a journalist in Turin (Italy), where I managed to find the strength to begin a long journey that is the purpose of my life: to ensure that the superstitions and prejudices that surround people like me will be once and for all, in the twenty-first century, defeated.

Every year hundreds of us disappear, as my brother Maurice, who disappeared more than 20 years ago. I don't know what I will get, but I'm sure that it is necessary to tell about albinism. I want to go back to Cameroon to retrace the places of my life and to cope with the symbols at the base of our suffering. I will reach the volcano's slopes to meet the wizard who believes that sacrificing albinos will placate the gods' wrath. Furthermore, I will visit the government buildings, meeting public administrators and politicians, that I already contacted. I helped also to build the "Bibliothèque Pavillon Blanc", a library dedicated to all albinos people and visually impaired people of Douala, my hometown. Thanks to the intervention of some Italian associations and foundations, in fact, I bought special computers and books printed in a larger font. And finally, the Bibliothèque was inaugurated on 28th January 2014 also thanks to the support of Fondazione 7 Novembre Onlus and Apri Onlus.

Stéphane's story is reported in the audio documentary "White Africa, from Cameroon to Piemonte – an albino's self-rescue" (by Barbara D'Amico and Fabio Lepore, listenable on <http://vimeo.com/51428950>). The audio documentary was awarded at the Bellaria Film Festival in 2013. And now, Stéphane's inquiry to the roots of African superstitions on albinism is also becoming a video documentary. Produced by Smart Factory with the support of Piemonte Doc Film Fund – Fondo regionale per il documentario, it will be released on 2015 (more info on www.facebook.com/stephane.thedocumentary).