



SOUTHERN AFRICA: Too white to be black - the challenge of albinism



Photo: Afif Sarhan/IRIN

John Makumbe has been fighting for the rights of people living with albinism for more than a decade

JOHANNESBURG, 16 February 2006 (IRIN) - Professor John Makumbe was almost killed at birth by a shocked mid-wife in a mission hospital in rural eastern Zimbabwe.

"Looking at how white I was, she assumed that my mother had been misbehaving with one of the white missionaries at the school where she taught," said an amused Makumbe, 57, who for the past 20 years has been a lecturer at the University of Zimbabwe. It was only after his mother explained to the mid-wife that the child had inherited a genetic disorder that the mid-wife relented.

Makumbe went on to form the Zimbabwe Albino Association (ZIMAS) in 1996. Tens of thousand southern Africans living with albinism have faced discrimination and abuse all their lives. They are often regarded as "unnatural" and even "cursed".

Albinism is an inherited genetic disorder in which the body fails to produce enough melanin. Because of the lack of pigment, the affected person has very pale skin, white or sand-coloured hair, and light brown or even blue eyes.

According to Professor Trevor Jenkins of the Department of Human Genetics at the South African Institute for Medical Research, one in 35 black southern Africans is a carrier of an albinism mutation. When both parents are carriers, the child is born with albinism.

People living with albinism often have impaired vision and sensitive skin, which makes them easy targets for abuse. In school, Makumbe was constantly bullied. His classmates would try to pull his hair out, "to see if I would bleed and if my blood was red".

Nomasonto Mazibuko, the founder of the Albinism Society of South Africa, remembers hurtful names like "Inkawu" (monkey) from her childhood.

"Children cannot read from the blackboard and have to constantly ask their classmates to help them. They get sunburnt within 20 minutes of exposure to the sun. In the absence of sunscreen lotions in rural Malawi, many develop lesions and people laugh and call them 'napweli' (tomato with black spots)," said Grace Massah, the chair of the Albino Association of Malawi.

Some parents in the countryside keep their children with albinism hidden from view, and it is not unknown for mothers of children born with the condition to be divorced, on the grounds that they caused the affliction.

The word "albino" is considered offensive, "people living with albinism" is the preferred term of reference. There are different types of albinism. Oculocutaneous albinism affects the hair, skin and eyes. While in ocular albinism, people could be born with normal skin and hair but with little or no pigment in the eyes.

The amount of pigment in the eyes varies. Although some individuals with albinism have reddish or violet eyes, most have

"There is a belief in Zimbabwe that if a pregnant woman looks at a person with albinism, she will give birth to a child with the same condition unless she spits on her stomach," said Makumbe, a political scientist and head of the Zimbabwean chapter of Transparency International.

Unlike in the United States, where one in 17,000 have some type of albinism, the disorder is not recognised as a disability in Southern Africa, despite the fact that the region has a particularly high incidence.

One in every 4,000 South Africans has the disorder, according to Mazibuko. "In South Africa, we have families of children living with albinism," including her own, with five of her siblings having inherited the condition.

Zimbabwe has around 14,000 people living with albinism, ZIMAS believes. "We need to unite the community and lobby for our rights regionally," said Mazibuko, a teacher.

She has been pushing the South African government and medical aid firms to subsidise sunscreen lotions and eye care for people with albinism since she founded her NGO in 1991. "Sunscreen lotions are still considered a luxurious item for white women - for us it is a necessity."

Skin cancer often proves fatal among people living with albinism. "At least 75 percent of the people in our community who I see at the clinic have skin cancer," said Massah.

About 65 percent of people with albinism in Zimbabwe are aged under 20. "Mortality is incredibly high - most of our people are aged between 33 to 50 years - very few people live beyond that, and it is sad because skin cancer is curable," commented Makumbe.

ZIMAS has successfully lobbied the Zimbabwean government to manufacture sunscreen lotion, but with the country struggling with a deep recession, the price is beyond the reach of most of the population. A bottle of sunscreen lotion sells for about US \$10, while average monthly salaries are around \$100.

Education and creating awareness of the genetic disorder is a major focus of activities of organisations working with the albinism community in the region. "The incidence of albinism is high in South Africa because the Tswana and the Sotho [ethnic groups] traditionally tended to marry their cousins," explained Mazibuko.

People living with albinism are discouraged from marrying others with the same disorder. Attempts to educate the world outside their community is as important. "Being born white in a black community has its share of problems - you do not fit in," commented Makumbe.

Discrimination at work is common. "People assume you are weak and will constantly be sick - so they do not hire you", noted Massah.

Mazibuko recalls being overlooked for promotion as deputy principal, because the teachers at her school did not want an "albino" as their head. "We do not melt in the rain, we do not disappear - we live and die like normal people," said an exasperated Massah.

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