



Albinism in Africa

*'My people are destroyed for lack of knowledge because they have rejected knowledge.'*¹

1. Introduction

This statement could be true for persons with albinism (PWA), who suffer various forms of discrimination due to lack of knowledge and understanding on the part of the wider community. Historically, African populations were not aware of the cause of albinism, as health science on the continent was not sufficiently developed to provide the necessary biomedical information.

Additionally, African cultures, beliefs and superstitions reinforced discrimination against people with albinism leading to, amongst other things, the violation of their rights to life, health, education and work. For instance, midwives or nurses might abandon a black woman giving birth to a white-skinned child (or an 'albino', as a person with albinism is commonly referred to; this term is now regarded as pejorative, and instead we generally refer to 'people with albinism').

The phenomenon of albinism raises a number of questions: to what extent does contemporary African society understand the cause of albinism? How does the condition affect the human rights of the people who have it, and indeed, their perceived humanity? What are the causes of albinism? And what are the prejudices associated with it?

This paper will respond to these questions from the social, medical and legal perspectives, and will hopefully help to inform people about albinism. This is a vital step towards promoting and protecting the rights of people with the condition.

It will also attempt to suggest some recommendations to reduce prejudice and discrimination against such individuals by mentioning the duties and responsibilities of families, African governments, regional organisations and NGOs.

¹Hosea4:6

The paper will first examine the cause of albinism through biomedical information. Secondly, it will consider the prevalence of albinism, and analyse the human rights situation related to the condition. It will also discuss the understanding of albinism through African cultures, beliefs and superstitions and, finally, it will offer some recommendations.

2. The Cause of Albinism

The science of genetics provides exact information on albinism: 'Albinism consists of a group of genetic disorders of the melanin pigmentation system which occurs throughout the animal kingdom from insects, fish and birds right up to human beings'.² In other words, albinism does not exist only in human beings, but in all animals. (Indeed, albinism can also occur in plants due to a lack of chlorophyll.) A very important part of this definition is that albinism exists in all parts of the world, and in all life forms. It certainly does not exist only in Africa; all continents have a population of people with albinism.

Albinism is characterized by an absence of, or decrease in, melanin, which in the human varieties of albinism takes two forms: (i) oculocutaneous albinism and (ii) ocular albinism. The first form (which is by far the commoner) manifests as a lack of pigmentation in the skin, hair and eyes. In ocular albinism the loss of melanin is limited to the eyes, while skin pigmentation is normal. As is commonly known, pigmentation naturally differs between human beings, rendering some people darker-skinned, and others fairer, depending on their melanin levels. Thus, low levels of melanin cause an absence of pigmentation and may result in a child being born with albinism.

A similar explanation of albinism states: "The human body's production of melanin is governed by many factors, including pigmentation genes, hormones and ultra-violet radiation (UVR). When the action of genes and hormones is not in balance an individual's melanin production can be completely or partly disrupted, causing the person to have little or no pigment in his or her skin, hair or eyes; in other words to become an albino".³

Generally, the lack of pigmentation affects the skin, hair and eyes. Hair will look reddish or yellow, and the skin will lack colour, tending to white. The skin burns easily on exposure to the sun, with a high risk of skin cancer.

Moreover, the nature of albinism means that all those with the condition have visual problems. There is hypopigmentation of the iris choroid and retina, as well as mal-development of the fovea (a part of the retina that mediates central vision). The typical signs of visual problems are photophobia (an abnormal, often painful, sensitivity to sunlight leading to its avoidance), nystagmus (involuntary rhythmical oscillations of the eyeballs, usually in a horizontal plane), squint, and decreased visual acuity.⁴

² Ashley H Robins *Biological Perspectives on Human Pigmentation* (1991) P 139

³ Nina G Jablonski *Skin A Natural History* (2006) P 69.

⁴ Ashley H Robins (Note ii) P 139

For these reasons, people with albinism often struggle with their eyesight. The prescription of correct spectacles and tinted glasses may help to reduce photophobia and improve vision, although they cannot address the underlying causes. The lenses are usually prescribed for a person from six years of age and must be renewed every two years in order to improve the vision. Unfortunately, even the cheaper lenses cost between 350 and 600 Euros (up to R8 000), an amount equivalent to the monthly salary of middle or senior professional in some parts of Africa. Consequently, most families simply cannot afford to buy the lenses, and the child concerned will struggle to improve his or her education. This is an important factor behind the high school drop-out rate of children who have the condition.

In addition, people with albinism must take strict precautions against sun exposure whenever possible. The sun should be avoided particularly between the hours of 10:00 and 15:00 in summer in South Africa, and 08:00 to 16:00 in tropical countries in East, West, Central and Southern Africa. Apart from protective clothing and the use of physical barrier creams, regular inspection of the skin (at least yearly) is needed in order to detect incipient malignant change.

The psychosocial aspects of the condition deserve special attention. Children with albinism and their parents require specific counselling about the problem of albinism and the relevant management strategies.⁵ In some parts of Africa the development of health science is beginning to explain to families with albinism what the causes and medical consequences of albinism are, but teaching the wider community about albinism remains a challenge.

3. The Prevalence of Albinism

The available data on albinism in Africa was collated some years ago, and there has been little additional research recently. It is thus possible that the prevalence figures may have changed due, for example, to overall population growth.

The estimated frequency of oculocutaneous albinism varies among different ethnic groups and in different geographical areas. For example, among European and North American Caucasians the frequency usually lies between 1 in 10 000 and 1 in 20 000, while among African Americans it is about 1 in 10 000.⁶

Albinism appears to be more common in Africa, with the highest prevalence being about 1 in 2 000 in Tanzania.⁷ The reason for the high prevalence in Tanzania is not clearly understood. There is a rate of 1:5 000 in Nigeria and 1:3 900 in South Africa. In South Africa consanguinity appears to be a significant factor, for example being very high (42%) among the parents of Tswana albinos (the Tswana social system encourages marriage between cousins). The Southern Sotho also have a very high prevalence, as much as 1:2 000, while among the Zulu and Xhosa it is 1:4 500.

⁵ Ashley H Robins (Note ii) P148

⁶ Ashley H Robins (Note 1) P139

⁷ www.underthesamesun.org prevalence of albinism in Tanzania, accessed on 24 May 2013

In African cultures where marriage between cousins is encouraged the gene of albinism may spread in the family. One advantage of this is that the family will understand the cause of albinism and take greater care of the person affected. Conversely, in cultures with less prevalence of albinism, such people will likely suffer more prejudice and discrimination in the community.

4. Human Rights Perspectives

People with albinism are human beings and are entitled to enjoy the same human rights as everyone else: for our purposes, the rights to life, health, education, work, and equal opportunities are especially important. These human rights are set out in many international covenants which are in force in many African countries, such as the International Covenant on Civil and Political Rights (ICCPR),⁸ the International Covenant on Economic, Social and Cultural Rights (ICESCR),⁹ the UN Convention on the Rights of the Child (UNCRC),¹⁰ and the African Charter. In addition, they qualify as disabled persons and are consequently entitled to enjoy the specific rights and considerations mentioned in the UN Convention on the Rights of Persons with Disabilities (UNCRPD).¹¹ Article 10 of this convention reads: 'States Parties reaffirm that every human being has the inherent right to life and shall take all necessary measures to ensure its effective enjoyment by persons with disabilities on an equal basis with others.'

4.1. The right to life

This right is sacrosanct, and the supreme right according to Article 6 of the ICCPR; it is also mentioned in many African constitutions. In a religious context, every human being is considered sacred. But the right to life means more than just not being murdered; it includes the right to a decent life, the right to have some freedom in relation to the manner in which one lives one's life, the right to be treated equally in relation to those life choices, and so on.

However, people with albinism do not enjoy the right to life in some parts of Africa. For instance, in East Africa, specifically in Tanzania and neighbouring countries, they are not free to live in rural areas because of regular attacks on them (often for their body parts) and because of the trafficking of children with albinism.¹² This situation constitutes a violation of the right to life of PWA mentioned in the above conventions and Constitutions; and it clearly offends against article 10 of the UNCRPD, set out above.

4.2. The right to health

The traditional medical definition of 'disability' does not recognize albinism as a disability. However, with the introduction of the International Convention on the Rights of Persons with Disabilities, which mentions visual impairment, it is clear that the condition of albinism falls in

⁸ GA Res 2200 A (XX) 16 December 1966, entered into force in 1976

⁹ GA Res 2200 A (XX) 16 December 1966, entered into force in 1976

¹⁰ GA Res 44/25 of 20 November 1989, entered into force 2 September 1990

¹¹ A/Res/61/106/ UN General Assembly resolution adopted on 24 January 2007

¹² www.underthesamesun.org, trafficking of children with albinism, accessed on 24 May 2013

this category. Therefore, people with albinism should enjoy the same treatment as other disabled persons. However, policy-makers in different countries have adopted an inconsistent approach to this question: in some, they are regarded as disabled, but not in others.

The definition of disability is a contentious one. As Asch observes, terms such as “health, normality, impairment and disability are highly contested. Their meanings are not clear, objective, and universal across time and space, and are contentious even for contemporaries in the same culture, profession and field”.¹³

In addition, the early medical definitions of disability emphasised the physical, psychological and/or neurological nature of the disabled body. “Disability was equated with deficiency, in the sense that a physical, psychological and or neurological attribute was identified as lacking from an agreed-upon image of the ideal subject.”¹⁴

Further, disability policy is often designed and controlled by non-disabled functionaries at international and national level. Most importantly, the paradigm of disability policy has shifted from the medical welfare model towards the concept of independent living. According to this philosophy, disabled persons are the best experts about their own concerns and are citizens with rights and responsibilities.¹⁵ The modern concept of disability has allowed people with albinism to claim recognition and to assert their right to health regarding the barriers, prejudices and discrimination they face.

The right to health is mentioned in Article 12 of ICESCR. If this right were to be extended fully for people with albinism, they would be entitled to receive free sunscreen and free spectacles from the government as prevention against skin cancer. Article 2 of UNCRPD mentions the use of large print, human reader, and augmentative and alternative modes of communication for people with disabilities. Some of these mechanisms are applicable to visually-impaired people with albinism.

From this perspective, people with albinism are disabled persons. However, this recognition is not universal; in some countries where disabled persons receive a disability grant, such as in South Africa, people with the condition still struggle to get the grant due to a lack of recognition of their condition as a disability. In South Africa, the leading organization that represents disabled persons, the Disability Alliance of South Africa (DASA), does not mention albinism; neither does Disabled People South Africa (DPSA).¹⁶ This absence of recognition of albinism as a disability which is different from blindness has an impact at policy level, in terms of which it is not clear which government department to approach in order to discuss the issue of person with albinism.

¹³ Luke clement and Janet Read *Disabled People and the right to life: The protection and violation of disabled people’s most basic human rights* (2008) P 13

¹⁴ Brian Watermeyer, Leslie Swartz *Disability and Social Change, a South African Agenda* (2006) P149

¹⁵ Theresa Degener *Human Rights and Disabled Persons, Essays and Relevant Human Rights Instruments* (1995) 10

¹⁶ www.dpsa.org/partnerships disabled person’s organization of South Africa, accessed on 24 May 2013

4.3 The rights to education and work

Article 24 of the UNCRPD mentions the right to education of persons with disabilities, while Article 11 of the UNCRC recognizes the right to education of the disabled child.

The UNCRPD promotes the concept of mainstreaming to reduce prejudice and extend the understanding of disabilities. Mainstreaming is a concept that can be reduced to a simple notion that 'interaction between individuals with or without disabilities is helpful in the long run, since we are all part of one society, and we want the student with a disability to feel a part of, and ultimately participate in, the society.'¹⁷ In some countries people with albinism study at mainstream institutions, where they should be provided with large print and assistive devices. In South Africa, there is a need for a deeper understanding of the disability aspects of albinism in order to accommodate these students better. At present, in South Africa most children with albinism study in special schools or schools for the blind. They should have specific devices, different from those used by blind learners, such as computers with 'zoomtext' and a Merlin Large Printer.

People with albinism have the right to work and the right to equal opportunities. However, these rights are sometimes in conflict with African cultures (see below), which can result in them finding it very difficult to secure employment. In countries which have affirmative-action employment policies for disabled people, such as South Africa, people with albinism may benefit, provided that they are aware of these policies and are recognised as disabled.

5. Understanding of Albinism in African Cultures and Beliefs

African cultures have developed many beliefs to understand the condition of albinism. 'Culture is a system of beliefs and practices in terms of which a group of human beings understand, regulate and structure their individuals and collective lives. It is a way of both understanding and organizing human life'.¹⁸ In other words, each part of Africa has its culture and beliefs. However, in general all cultures have some similarities and beliefs regarding people with albinism.

In central Africa for instance, such people were regarded as mysterious persons with specific powers and intelligence, and as bringers of good luck in the family.¹⁹ In Southern Africa several myths exist in relation to the powers and the fate of people with albinism: For example, that they have special spiritual powers and will not die naturally, but just disappear when the time comes; that albinism results from a black woman sleeping with a white man; and that having intercourse with a woman with albinism cures HIV/AIDS (with the result that many such women are at high risk of rape). Another belief is that if a pregnant women looks

¹⁷ Robert A Weisgerber *Quality of Life for Persons with Disabilities* (1991) P 71

¹⁸ Bhikhu Parekh *Rethinking Multiculturalism, Cultural Diversity and Political Theory* 2ed (2006) P 143

¹⁹ Ashley H Robins (Note 1) P180-81

at a person with albinism, she will give birth to a child with the condition unless she spits on her stomach.²⁰

In evaluating the impact of the birth of a child with albinism on black South African mothers, the mothers were initially depressed and uncomfortable at being in close contact with their infants, and reluctant to breastfeed them.²¹

In West Africa, there is a belief that people with albinism put their countries under divine protection. In East Africa, in contrast, albinism is regarded as a punishment to the family, and children with the condition were at one time perceived as curiosities and kept in the households of kings and great chiefs.²² In all parts of Africa, people with albinism have been subject to labelling with terms such as 'monkey' or 'ghost'.

From this perspective, the respect and dignity of people with albinism will depend upon where in Africa they live. In some parts of the continent, they are treated as human beings with equal rights, while in other parts, such as East Africa, they are treated as 'sub-human'. For instance, employers avoid hiring a person with albinism due to fears that their customers and staff will 'catch the condition or that food will be contaminated'.²³ As a result, despite having qualifications, they often will not get a job and therefore families do not bother to educate or take care of children with the condition.

Moreover, African culture places the responsibility for the albinism gene on women, and not the man, meaning that when a child is born with the condition, the woman carries the burden. As we shall see, apart from being unfair to the mother, this belief is also scientifically inaccurate.

5.1 The responsibility of parents

The genetic definition of albinism demonstrates that both parents are responsible for passing on the condition. The two types of albinism are transmitted by Mendelian recessive inheritance. This means that a person with albinism must have received it from both parents. If the clinically normal parents of a person with albinism are heterozygous carriers of the albinism gene then, according to Mendelian genetics, the pairing of two such heterozygote carriers will result in a 1 in 4 probability that their offspring will have the condition. If both parents have albinism then all of their offspring will have it.²⁴

Accordingly, to give birth to a child with albinism both parents must carry the gene of albinism. If only one parent carries the gene they cannot give birth to child with the condition, but may well transmit the gene of albinism. The next generation will be ignorant of being carriers of the gene of albinism, but if one of them should procreate with another carrier of gene, they might give birth to a child with albinism. And if both parents actually have albinism, then all their offspring will also have it.

²⁰ www.hst.org.za Southern African beliefs on albinism, accessed on 22 May 2013

²¹ Ashley H Robins (Note 1) P 180-81

²² Ashley H Robins (Note 1) P 180-81

²³ www.underthesamesun.org beliefs on albinism, accessed on 24 May 2013

²⁴ Ashley H Robins (Note 1) P 141

Although both parents are responsible for passing on the gene, in African culture, children with albinism experience different treatment according to whether the family regime is matrilineal or patrilineal.

5.2. Matrilineal family

Matrilineal family comes from *matri* meaning maternal and *lineal* meaning lineage. Lineage deals with your kinship grouping or family tree. In some African societies inheritance is also matrilineal, which implies that upon a man's death his sister's son will inherit his material goods and position. Here a child has the family name of the father or the name of the family's mother.²⁵

A child with albinism born into a matrilineal society may receive affection, education and protection. The mother can breastfeed the child and take care of it because the child is part of her 'social security', and will contribute to her family. In circumstances where the father has denied the child because of albinism, family on the mother's side will take care of it; the child will not suffer prejudice or rejection, and the community will respond in the same manner. The mother will praise God to have the child, feed her baby and carry it "Moukanga", by putting the baby on her back while she works. This attitude of love and care of the mother will be a message to the community which, in turn, will follow the example of the family.

From this perspective, there will be joy, happiness, and respect for the dignity of the child and non-discrimination towards the family from the community. However, the opposite can occur in a patrilineal family.

5.3. Patrilineal family

According to article 312 of the civil code of French law, which has been taken up in many former French colonies in Africa, there is a presumption which means the father may deny the child, even in court. In such case, the child will not know his or her paternal family, and the maternal family may also reject the baby. Consequently, the child from birth will suffer prejudice and rejection by both families. This attitude leads many mothers to hide the child from the view of the community by keeping the child indoors and not informing the community about having such a child. In this way, some children with albinism are treated as aliens in the family and in the community. The discrimination starts from home and the community follows the negative attitude of the family.

This leads to much prejudice and suffering. For instance, the child will not receive attention for his/her education because of the prejudice that having low-vision means stupidity. Children born in these conditions will tend to lack self-esteem. The prevailing attitude will be, "How can you spend money on someone who cannot see? This child cannot watch cattle or work in the plantation. Therefore, the child is useless." These powerful words will have an impact on the growth and development of the child by limiting its chances of success and self-fulfilment.

²⁵ Luke Clement (Note 12) P 250

In general, African cultures still rely on beliefs and superstitions to make sense of the condition of albinism. But this situation differs from one part of Africa to another. While in some parts the rate of acceptance seems to improve, in other parts the situation is critical, as in East Africa, where discrimination and rejection of people with albinism have escalated in the last decade. Thus, there is an urgent need for African governments, regional organisations, and NGOs to act to end prejudice and discrimination against people with albinism in Africa.

6. A Way Forward

The end of prejudice and discrimination must start in the families of people with this condition. But it is equally important that African states commit to ending discrimination as part of their international obligations.

6.1. The role of the family

Families should:

- be given accurate information on the condition of albinism from professionals;
- join non-governmental organizations dealing with the issue of albinism, in order to educate and advocate for the rights of children with the condition;
- form a support group to inform each other on the daily challenges of children with albinism;
- always be in touch with the schools that the children attend;
- have a duty to communicate with the child and take care of it by encouraging, stimulating and supporting the initiative of the child.

6.2. The role of governments

- African governments should:
- Recognize all forms of disabilities;
- Raise awareness of albinism through social media;
- Promote the visibility of people with albinism in the public administration, so as to reduce prejudice and discrimination;
- Encourage research about albinism;
- Provide sunscreen and spectacles to those with the condition, and assistive devices to learners;

- Encourage and assist NGOs run by people with albinism themselves to raise awareness and educate the community at large;
- Encourage the private sector to hire people with albinism and to promote equal opportunities.

6.3. The duties of regional organizations

The African Union should:

- Take seriously the issues of prejudice, discrimination and killings of people with albinism. The UN Human Right Council (UNHRC) in its 23rd session has adopted a resolution condemning brutal attacks and discrimination against people with the condition. It ‘urges States to take all measures necessary to ensure the effective protection of persons with albinism, and their family members’²⁶ Consequently, the AU has a responsibility to implement this historic resolution to end the flagrant violation of the rights of people with albinism in Africa;
- Establish a pan-African albinism organisation to work with African leaders to better understand the cause of albinism and to end prejudice and discrimination in all African cultures towards people who have the condition;
- Promote human rights education at school and universities in order to understand the condition of albinism;
- Raise awareness of albinism.

6.4. The duties of non-governmental organizations

Non-governmental organizations should:

- Inform parents of children with albinism about the condition and form support groups to develop the self-esteem of such children;
- Counsel and advice families;
- Work with medical expert, schools, universities and churches to educate the wider community on the condition of albinism;
- Assist teachers to understand albinism by putting these children close to the blackboard and giving learners a copy of large-print materials;
- Promote and advocate the rights of people with albinism;
- Suggest policy and legislation related to people with albinism;

²⁶ A/HRC/23/L25 on 10 June 2013

- Lobby for better understanding of albinism;
- Work closely with other civil societies such as churches to educate the community at large.

6.5. The role of the churches

- Churches have played an important role during decolonisation and apartheid in Africa. Today, they still have the moral authority to educate the community at large. Therefore, churches should work to end the beliefs and superstitions mentioned above. By faith, we are all children of God, and also by creation, conservation and by redemption. We are all created by God and all that God made is good (Genesis 1).
- Churches should promote the principle of love highlighted in Jesus' teaching, "Love God and love your neighbour" (Matt 5;11). The churches have a mission of making known the truth and leading people to the truth, and the truth is to consider people with albinism as part of God's creation and to end all forms of discrimination based on their skin colour.
- Moreover, not only churches, but also the testimony of the Holy Qur'an says, "stand out firmly for justice, as witness to Allah..." (Holy Qur'an 4; 135). Justice is a divine mission.

7. Conclusion

An understanding of albinism is crucial if we are to end prejudice and discrimination. This becomes possible through the involvement of all stakeholders – African governments, regional organizations, NGOs, schools, churches and families. The promotion and protection of the rights of people with albinism must be carried out in a way that takes account of African cultures. Finally, as the responsibility is not only with people with albinism themselves to end the prejudice, but with the wider community, no-one should stand idly by when lives are in danger – Act Now! (Leviticus 19-16).

Narcisse Kimbassa

Narcisse Kimbassa, born in Congo-Brazzaville, holds a Master's degree in International Law from the University of Cape Town. He is currently legal officer at the Western Cape Albinism and Hypo-pigment Foundation (WCAHF), and a legal intern at the SA Human Rights Commission. Mr Kimbassa conducts workshops, seminars and education on the rights of persons with disabilities and on issues concerning albinism. He can be contacted at nkimbassa@yahoo.fr

Further Reading

- 1 - Ashley H Robins: *Biological Perspectives on Human Pigmentation*, Cambridge Studies in Biological Anthropology, Cambridge University Press, New York, Melbourne, Sydney, 1991
- 2 - Bhikhu Parekh: *Rethinking Multiculturalism Cultural Diversity and Political Theory*, second edition, 2006
- 3 - [http://www.hst.org.za/news/southern Africa](http://www.hst.org.za/news/southern%20Africa): on the culture of albinism
- 4 - Nina G Jablonski: *Skin: A Natural History*, University of California Press, 2006
- 5 - www.underthesamesun.org: beliefs on albinism
- 6 - Luke Clements and Janet Read: *Disabled People and the Right to Life: The Protection and Violation of Disabled People's Most Basic Human Rights*, Routledge, Taylor and Francis Group, 2008
- 7 - Robert A Weisberger: *Quality of Life for Persons with Disabilities*, Aspen Publishers, 1991
- 8 - www.dpsa.org/partnerships.php

This Occasional Paper, or parts thereof, may be reproduced with acknowledgement.
For further information, please contact the CPLO Office Administrator.