



Understanding the critical health issues experienced by young people with albinism in Southern Africa

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Introduction

Young people with albinism face a myriad of health challenges in Southern Africa. Despite the availability of a wide range of medical information about albinism and health, most of this information is projected in formats that are not accessible to lay persons. This article attempts to simplify information about albinism. The article will introduce the topic of albinism by providing a definition of albinism and the prevalence rate of this

condition. A discussion of the health challenges faced by young people with albinism will follow. Issues such as low vision, skin-related challenges and mental health challenges will be discussed.

What is albinism

Albinism is an inherited genetic condition that is characterised by the reduction of the pigment melanin formed in the skin, hair and/or eyes. Melanin is a type of protein required by the skin to absorb ultraviolet light. The term albino comes from the Latin word “albus” which means white (Kromberg & Manga, 2018).

There are two main types of albinism: Oculocutaneous Albinism (OCA) and Ocular albinism (OA). Oculocutaneous affects the skin eyes and hair while Ocular Albinism (OA) affects only the eyes (Mabula et al., 2012). However, the most common type of albinism found in Sub-Sahara Africa is Oculocutaneous Albinism. Albinism occurs in all races and ethnic groups in Africa. Both parents must carry the albinism gene for a child with albinism to be conceived. This is contrary to certain African societal myths that tend to blame women for having a child with albinism Some myths go further to associate the birth of a child with albinism with evil spirits and curses which is not true.

Prevalence of Albinism

In Southern Africa, data on the prevalence of PWA is disaggregated. Most countries in Southern Africa do not have official statistics on the number of people with albinism in their country. According to the United Nations Independent expert on albinism’s 2019 report, the prevalence rate of PWA is estimated to be between 1 in 5000 to 1 in 15 000 in Africa and 1 in 1000 in Southern Africa. Franklin et al. (2018) placed the prevalence of PWA in Southern Africa between 1 in 2 000 to 5 000, and the proportion of school children with albinism is estimated to be between 1 in 2 000-4 000.



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Low vision



One of the most common challenges associated with albinism is low vision. Existing research shows that people with albinism have low vision problems that cannot be corrected with low vision aids such as spectacles. The presence of impaired sight is a key factor in the diagnosis of albinism. Research shows that this form of impairment is caused by the abnormal development of the retina. It must be noted that the extent of eye impairment is not the same for all people with albinism. Some people with albinism tend to have improved vision than others. Research shows that people with albinism especially learners in school settings are often perceived to be slow learners. This is mostly because many teachers don't understand the low vision needs of these young learners. Studies show that learners with albinism need to sit in front of the classroom in classes where blackboards are utilised. Learners with albinism also need to use their own textbooks because they have to look closely at the textbooks hence, sharing reading books is not ideal for their eyesight. It is also important to note that with low vision aids such as spectacles, magnifiers, monocular and other digital assistive technologies, people with albinism can excel and reach their full potential.

Some of the common characteristics of the eye impairment of people with albinism include Nystagmus, the involuntary movement of the eyes,

Strabismus: referring to a muscle imbalance of the eyes, (crossed and lazy eye and Photophobia: Sensitivity to bright light and glare.

Skin related challenges

People with albinism experience many skin challenges related to the condition of albinism. challenges, that prevent them from leading a normal life One of these problems is, that they are easily susceptible to skin cancer. The skin of albinos is sensitive to sunlight. Continuous exposure to the sun leads to them having sunburns and it increases their risk of getting skin cancer. Because of the deficit of melanin, the skin of PWA is easily damaged by the sun. As a result, blisters on the skin or a distinct redness are some of the signs of the harmful effects of the sun and the skin of people with albinism. Repeated exposure to the sun also leads to pigmented freckles small, flat, brown spots on the skin and the risk of skin cancer. Research shows that skin cancer is the number one killer of people with albinism in Africa. Some studies further show that life expectancy of people with albinism is low and the majority of them do not live past the ages of 30 to 40 years because of diseases such as skin cancer.



A study by Lund in (2008) found that young people with albinism are at greater risk of sun exposure and skin cancer risk. The study found that high exposure to the sun often resulted in sunburn, blistering, dryness and chapping of the lips which also led to



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infections. To ensure that good skin health is maintained, people with albinism need to check their skin regularly to detect any changes in their skin at an early age. Parents or caregivers of children with albinism also need to regularly monitor the skin of their child for lesions, blisters, spots, sunburns etc.

Research shows that putting on sunscreen lotion is one of the most common ways of preventing sun damage and skin cancer. These screen lotions have chemicals that can protect the skin from the harmful effects of the sun. In Southern Africa, sunscreen lotions are available in various brands and are usually identified by their Sun Protection Factor (SPF). The more the SPF in a lotion, the greater the protection from the sun. much Research shows that many dermatologists recommend sun creams with an SPF of 30 or higher. The application of lip balms of SPF 30 or higher is also encouraged because the lips of people with albinism tend to be highly exposed to the sun (Kromberg et al., 2020). Doctors also recommend that PWA wear protective clothing to complement sunscreen lotions. Long-sleeved shirts, trousers, long-brimmed hats and limiting outdoor activities are encouraged for protecting people with albinism from the sun. Wearing caps is discouraged because it leaves other areas of the face unprotected from the sun.

Studies have shown that the wearing of protective clothing is not popular amongst young people with albinism. Young people with albinism often prefer to wear stylish clothing such as baseball caps, clothes with no arms, miniskirts, and shorts instead of long-brimmed hats and long-sleeved shirts. This is because these young people want to fit in with their peers and they don't want to stand out and be ridiculed by their peers. This is common because of the stigma they face in society, however, failing to wear protective clothing goes against recommendations by doctors and it has long-term effects on their skin health (Opara & Jiburum, 2010).

Access to skin specialists such as dermatologists is also crucial to the prevention and treatment of skin cancer. Research shows that regular check-ups by dermatologists are essential for people with albinism. However, in Southern Africa research shows that access to skin specialists is expensive. This affects the early detection and treatment of cancers.

Apart from the difficulty to access dermatology services, another challenge affecting the prevention of skin cancer amongst people with albinism in Southern Africa is the limited access to sunscreen lotion. In most countries in Southern, Africa governments are not providing easy access to sunscreen lotions. In cases where sunscreen lotions are provided in hospitals, there is usually a short supply of these creams. In many Southern African counties, people with albinism residing in remote areas are not accessing these lotions. Some must travel very long distances in the scorching sun to access a few bottles of sunscreen lotion. In some countries, sunscreen lotions are very expensive to acquire for many people with albinism who are living in abject poverty. Resulting in many people with albinism failing to have access to these lifesaving lotions (Kromberg et al., 2020; Zungu & Mashige, 2019).

Albinism and mental health

Research shows that majority of people with albinism experience serious mental health challenges because of stigma and discrimination. Because of their unique physical appearance. In many countries in Southern Africa, dehumanising names are used to describe persons with albinism because they are different from most of the population which is dark-skinned. In countries such as Malawi, some communities use the word *mzungu* meaning 'white man' to describe a person with albinism while in countries such as South Africa and Zimbabwe, names such as *leswafi* (Monkey), *musope* (white). In Tanzania, the labels *zezuru* (ghost) or *mlanga*



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(transparent) are also used to describe persons with albinism. Apart from name calling certain false beliefs continue to circulate in African communities. Some African beliefs associate people with albinism with witchcraft or money-making charms. This has either resulted in the killing of people with albinism for ritual purposes or the stigmatisation and exclusion of this group in many African communities. All this has led to serious psychological problems for people with albinism, especially young people (Baker et al., 2010).



Conclusion

The discussions in this article have highlighted some crucial health issues to be considered when dealing with young people with albinism. The article looked at low vision issues, skin cancer-related issues and mental health issues. The paper also highlighted some of the preventative measures related to skin cancer, low vision considerations and the contextual challenges affecting the health outcomes of persons with albinism in Southern Africa. In conclusion, persons with albinism can live an autonomous life, there is a need for various stakeholders such as governments and non-governmental organizations to come together and devise policies that improve the health outcomes of persons with albinism in Southern Africa.



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