Albinism in Africa: a medical and social emergency

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People with albinism (PWA) face a variety of medical and social problems, ranging from poor vision and skin cancer to murder for their body parts for witchcraft in East Africa, notably Tanzania. Albinism is an inherited disorder of melanin biosynthesis that results in a variable phenotype classified according to the mutation in one of several genes.

All forms of albinism are associated with problems of the visual system resulting in abnormalities of the retina, nystagmus, strabismus, foveal hypoplasia, abnormal crossing of the optic fibers, photophobia and reduced visual acuity.1 Oculocutaneous albinism (OCA) is a subgroup of recessive forms of albinism and characterized by a significant reduction or absence of melanin pigment in the eyes, skin and hair.2 Several genes are associated with OCA, although the most common forms are OCA1 and OCA2. OCA1 is caused by a reduction or complete lack of activity of the tyrosinase enzyme encoded by the TYR gene. OCA2 is caused by a reduction or complete lack of activity of the P protein—a chloride channel that helps regulate the pH of the melanosome organelle where tyrosinase is active.3,4 Although OCA2 is found in all populations, certain populations have a relatively high incidence. The worldwide incidence of OCA2 is 1 in 36,000, but it is especially common among individuals of African descent.5 The phenotype of sandy colored hair, chalky white skin and blue or hazel eyes is very distinctive in African populations (Figure 1).5 High OCA2 frequencies are seen among various African tribes: 1 in 1100 among the Ibo of Nigeria,7 1 in 7900 among the Bamileke of Cameroon,8 1 in 3900 in South Africa9 and 1 in 1400 in Tanzania.10 Therefore, Tanzania has one of the world’s highest rates of albinism. The most common form of mutation among the OCA2 PWAs in Tanzania is a specific deletion of exon 7 of the OCA2 gene accounting for 77% of the mutant alleles.10 This same mutation is commonly found among other Africans and African-Americans5,6,8,10 and appears to be derived from a common African ancestor who lived 2000–5000 years ago.5,9

In addition to their vision problems, PWAs are also highly susceptible to skin cancer with high rates of squamous and basal cell carcinoma.11,12 Sunscreens are expensive and often unavailable in many parts of Africa, so health intervention strategies mainly focus on encouraging sun avoidance and protection from an early age.6 Historically, some tribes have killed newborns with albinism and those that survive are often discriminated against as marriage partners. Since people with albinism have fewer children, as a result of murders and social customs, there must be a reason that heterozygous frequency for OCA2 is so prevalent, especially in Tanzania. One possible insight derives from the observation that the OCA2 protein shares amino acid homology with 3BL, a protein of unknown function in the Mycobacteria,13 such as Mycobacterium leprae, the bacteria that causes leprosy or Hansen’s disease. Moreover, among the first signs of leprosy are hypopigmented patches, suggesting that pigment cells may play a role in the etiology of the disease. Leprosy has been historically high and endemic in Tanzania, where OCA2 and carriers for OCA2 are also very high.13 Thus, there is circumstantial evidence for a relationship between the high prevalence of OCA2 and leprosy.

Sadly, in the past few years, PWAs in Tanzania face an additional threat. They are being murdered at an alarming rate for their body parts (primarily bones and hair) used for witchcraft purposes. Local superstition holds that the bones, hair and other body parts of a PWA can be used in potions believed to be magical for success in finding things, such as in mining. In the past, obtaining body parts was largely limited to grave robbing, but living people are increasingly targeted now for murder and mutilation for their body parts. In particular, the bones of a PWA are quite valuable for these witchcraft uses, with the highest price paid for the bones of children (Figure 2). While it is proper to respect rituals, beliefs and traditions that are not our own, the murder and maiming of innocent people can never be justified. Recently, under increased international pressure, the Tanzanian government has outlawed these practices by witch doctors, yet the murders and mutilations continue. Because of the high rate of OCA2 in Tanzania, 1 in 19 people are carriers for the ancestral mutation.13 Ironically, it is highly likely that this mutation is also carried by at least a few of the murderers of PWA. Perhaps if the people of Tanzania knew that PWAs are a manifestation of one of their ancestors, the murders would stop.

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There are NGOs and charitable organizations that advocate and defend PWAs. One shining example is ‘Under the Same Sun’ (www.underthesamesun.com) that provides inclusive education and safe havens for PWA, especially children who are often abandoned. Under the Same Sun is dedicated to advocacy and education from the grass roots level to government officials and international powers such as the United Nations and the African Union. Indeed, with advocacy from Under the Same Sun, the National Organization for Albinism and Hypopigmentation (USA), World Albinism Alliance, Standing Voice and the Salif Keita Foundation, the United Nations Human Rights Commission recently launched a campaign against the violence of PWAs in Africa (http://albinism.ohchr.org/ and http://www.ohchr.org/EN/HRBodies/HRC/AdvisoryCommittee/Pages/AttacksAgainstPersonsWithAlbinism.aspx). Investigating these attacks requires a resolute, systematic and combined approach. Since the investigative skills of police and journalist are frequently inadequate (or even absent) in countries like Tanzania, a primary source of information comes from their ‘First Responder Team’ which visits victims of attack, including their families and community, to investigate and record all relevant data related to the reported attack.

PWAs face enormous challenges in East Africa. They have very poor, uncorrectable vision and, as a result, they are disadvantaged in schools and in employment opportunities. At best, they are discriminated against; at worst, they are hunted and often killed for their body parts for witchcraft use. If they survive these attacks, they are very likely to develop skin cancer that is most often untreated, leading to a preventable premature death. However, awareness and activism can help PWAs to lead more normal lives by addressing their medical and social needs. Above all, we must all work to stop these atrocities against these people who suffer from a visible genetic condition.

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**References**


