

Deepening the Woes: The COVID-19 pandemic and the right to health of persons with albinism in Ghana

Andrews Kwame Daklo[*]

Abstract: The COVID 19 pandemic has increased stigma and discrimination against persons with albinism in Ghana with negative effects on their health.

Albinism is a rare, non-contagious genetically inherited condition at birth caused by a lack of pigmentation (melanin) in the hair, eyes and skin. This lack of melanin makes persons with albinism vulnerable to sun and bright light. Albinism is classified as rare because the genes are recessive, while the genes for normal pigmentation are dominant. The prevalence of albinism varies considerably by population. It is highest overall in Africa where its prevalence is estimated at around one in 5,000, while in Europe and the United States of America, it is one in 20,000
Persons with albinism face serious human rights violations, including infanticide, murder and cutting off body parts for ritual purposes. Moreover, bullying and teasing as well as probing questions about appearance are commonplace, contributing to social isolation, poor self-esteem and stress.

---

[*]Andrews Kwame Daklo is a disability rights advocate from Ghana with experience in human rights advocacy, focussing on albinism, programming and social work. Kwame holds a Master's in Human Rights and Democratisation in Africa from the Centre for Human Rights, Faculty of Law, University of Pretoria. He is currently the Albinism programmes coordinator at Engage Now Africa and Communications Officer at Africa Albinism Network.

Albinism and its associated health concerns

The little or no pigment in the hair, eyes and skin means that persons with albinism also experience health complications. The lack of melanin predisposes individuals to the effects of ultraviolet radiation from the sun with multiple consequences, including skin cancer and visual disorders. In addition, almost all persons with albinism have some visual difficulties due to the lack of retina pigment needed for normal optical system development. As a result, persons with the condition experience photophobia, myopia and other visual problems, including nystagmus and strabismus.

Skin cancer is a particularly significant threat to persons with albinism in Africa, where 90 per cent of those affected with the disease die before age 40. This is because any sun exposure without proper protection leads to skin burning, which may develop into skin cancer if not properly treated. The body parts most affected by skin cancer include the neck, face, arms and shoulders. The types of skin cancer among persons with albinism in Africa include squamous cell carcinoma (SCC), basal cell carcinoma (BCC) and melanoma.

As a result, persons with albinism need specialist healthcare services, including dermatology and optometry. Sunscreen lotions and protective clothing such as long-sleeve shirts, long dresses, wide-brimmed hats and sunglasses form part of the daily dress code of those with the condition. Therefore, a continuous supply of these products is essential to the health of persons with albinism.

Impact of the COVID-19 pandemic on access to healthcare for persons with albinism in Ghana

The onset of the COVID-19 pandemic led to the suspension of specialist healthcare services at public hospitals in countries across the globe, including Ghana. COVID-19 testing, treatment and prevention were prioritised over other medical services. As a result of this prioritisation as well as lockdown restrictions, persons with albinism could not access essential medications and healthcare services such as regular skin and eye care and sunscreen lotions.

Organisations like Engage Now Africa, which provide persons with albinism with sunscreen lotions and other protective clothing, were unable to organise in-person events to distribute these products during the pandemic.

The pandemic also halted skin cancer treatment due to large numbers of COVID-19 patients needing the attention of available health workers. Likewise, the 'covid scare' prevented many persons with albinism from visiting health facilities. Moreover, even when the number of COVID-19 patients subsided, the numbers needing specialist healthcare services were much increased, making it difficult for persons with albinism who have advanced stages of skin cancer to access timely treatment.

The pandemic also increased discrimination and stigma against persons with albinism in Ghana. It is interesting to note that some people harbour the belief that persons with albinism are carrying and spreading COVID-19 due to the colour of their skin. There were reported instances where persons with albinism were being tagged 'Coronavirus' with threats of attacks. These new waves of stigma resulted in increased mental health issues among this population.

Recommendations

Even though the COVID-19 pandemic overburdened the healthcare system, the government needs to be mindful that in addition to COVID-19 patients, others too need critical attention. Pandemic preparedness se therefore requires consideration of such issues. Most importantly, skin cancer treatment and palliative care for persons with albinism should be made accessible or heavily subsidised. Additionally, sunscreen lotions should be considered essential drugs, added to the National Health Insurance drug list, and made available to persons with albinism at no cost. It is also recommended that regular skin and eye screening services be provided to persons with albinism in remote areas.

The involvement of persons with albinism in decision-making is crucial to realising their health rights. Article 29 of the Convention on the Rights of Persons with Disabilities (CRPD) recognises the rights to participation of persons with disabilities in decision-making involving their health and wellbeing. The government needs to engage persons with albinism, especially during pandemic planning, to identify their needs. One of the benefits of such participation of persons with albinism in policy-making is that it helps them air their views on challenges they face.

More generally, the government and its agencies and departments need to intensify public education on albinism to promote understanding of the condition. This will help prevent the discrimination and stigma that persons with albinism encounter daily. It will also curtail the other harmful practices meted out to this population, hence protecting and promoting their fundamental human rights, including the right to health.