Securing health and wellbeing for children with albinism

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Comment

Albinism is broadly considered a rare disease and is estimated to affect between one in 17 000 and one in 20 000 people worldwide.[1] Albinism is common in Africa, particularly in sub-Saharan Africa, where one in 3900 people have oculocutaneous albinism type 2,[2] which affects the skin, hair, and eyes.[1] From early childhood, medical attention and care are needed to prevent permanent health-limiting conditions associated with albinism such as low vision. Skin damage from sun exposure and an extremely high risk of melanoma explain in part why mortality by age 40 years is so high (up to 90%) among people with albinism who do not receive appropriate medical care from an early age.[3, 4, 5] To mark the 10th anniversary of International Albinism Awareness Day, we reflect on the state of medical care and societal support for children with albinism in Africa

For children in Africa especially, the continuum of health implications of albinism is particularly complex, their needs extending beyond specialist care. Stigma, discrimination, and persecution associated with albinism lead to social isolation and medical neglect for malnutrition and HIV, malaria, and other infectious diseases. Grave violations of human and child rights include kidnapping, organ trafficking, abandonment, infanticide, mutilation, and rape of children with albinism.[3, 4, 5, 6] Such violations are unfortunately common in Tanzania, Mozambique, Malawi, Zimbabwe, and Burundi, where witchcraft activity and cultural beliefs label people with albinism as bearers of bad luck, dishonour, or disgrace or as possessing magical powers to bring success or cure lethal diseases.

In 2016, the African Committee of Experts on the Rights and Welfare of the Child (ACERWC) investigated the situation of children with albinism held in temporary holding shelters in Tanzania. Known as safe houses, these shelters were established in response to the increase in kidnapping, mutilation, and killing of children with albinism for ritual purposes.[7] The ACERWC noted a broad range of human rights violations of these children: family separation, poor accommodation, inadequate nutrition and basic provisions, physical attacks, and failure to provide medical care, education, and opportunity to play.7 A 2022 ACERWC fact-finding mission in Malawi assessed the nature and gravity of violations that children with albinism experience and included an explicit focus on children with albinism with existing health vulnerability—girls, unaccompanied children, internally displaced children, refugees, and asylum seekers.[8] In Resolution 19/2022 of the Working Group on Children with Disabilities,[9] the ACERWC refers explicitly to the "lack of accessible and affordable medical care" for children with albinism and urges governments to subsidise the cost of "protective gear and equipment" and provide psychosocial and medical support to survivors of ritual attacks.

During its 43rd Ordinary Session in April, 2024, the ACERWC collaborated with the UN Independent Expert on the Enjoyment of Human Rights by Persons with Albinism in hosting a day of general discussion on solutions to challenges for children with albinism in Africa. Across four panel groups, fruitful discussions covered the role of the UN in safeguarding these children and their rights, the extant regional legal protections, strategic litigation, the collaborative strategies with civil society, and the need for empirical data. In an outcome statement,[10] participants reaffirmed Resolution 19/2022 of the Working Group on Children with Disabilities and called on African Union member states to ratify the Protocol to the African Charter on Human and Peoples' Rights on the Rights of Persons with Disabilities in Africa and to domesticate the African Union Plan of Action to End Attacks and Other Human Rights Violations Targeting Persons with Albinism in Africa (2021–31).[11].

Despite this recognition of human and health rights violations experienced by children with albinism in Africa, and the increased vigilance by the ACERWC, change is slow and is still working against discriminatory social beliefs, witchcraft activity, and continued demand for the body parts of people with albinism. More than ever, civil society and intersectoral collaborative movements such as the African Albinism Network need support to continue advocating for the human and health rights of children with albinism and promoting their wellbeing and inclusion. Through capacity development and collaboration, civil society has a crucial role in providing paediatric specialist medical services for eye and skin care, in distributing health protection resources, such as sunscreen and hats, and in supporting families through education and livelihoods. Other advocates are communicating through art, social, and traditional media to raise public awareness and acceptance of albinism.

Ultimately, African Union member states need to take substantive action on law enforcement across the continent to protect the right to life and health of children with albinism. Human rights-based safeguarding actions and protections must be underpinned by political commitment to upholding the rights and best interests of children with albinism, as contained in Resolution 19/2022 and in the African Charter on the Rights and Welfare of the Child. Human rights advocacy and strategic litigation, public sensitisation, and deterrence of grievous bodily harm and death of people with albinism are crucial. Resourcing of medical care for children and adolescents with albinism, including preventive health care to stall early mortality, must be included in governmental health budgets.

The child health research community has much to offer to fulfil the needs and rights of children with albinism, starting with establishing robust estimates of the prevalence of albinism in Africa. Further research, in Africa and elsewhere, stands to benefit from co-production with children with albinism and their carers. Capturing lived experiences and the voices of children with albinism—and celebrating their stories—will teach us how to guarantee their protection with dignity and respect and enable them to flourish.

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