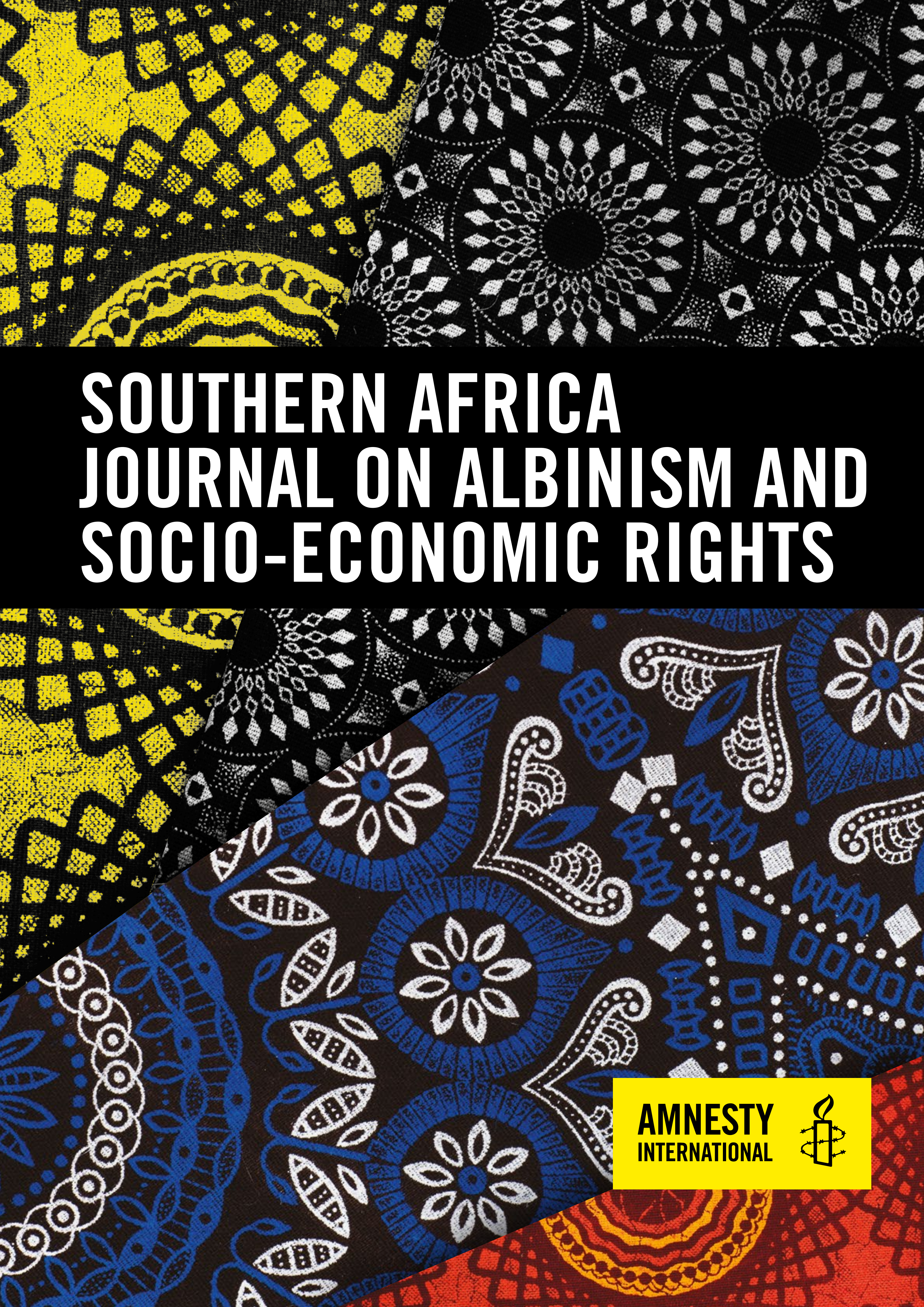

SOUTHERN AFRICA JOURNAL ON ALBINISM AND SOCIO-ECONOMIC RIGHTS

AMNESTY
INTERNATIONAL

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TABLE OF CONTENTS

ACRONYMS

AAN	Africa Albinism Network
ACCESS	Health Access Livelihood Framework
AFHESA	Atlantic Fellowship for Health Equity South Africa
AIDS	Acquired Immunodeficiency Syndrome
ALCOZ	Albino Charity Organization of Zimbabwe
APAM	Association of Persons with Albinism in Malawi
AU	African Union
AZEMAP	Associação Zé Manuel Pinto
CBD	Central Business District
CCTV	Closed-circuit television
CEDAW	Convention on the Elimination of All Forms of Discrimination Against Women
COVID	Coronavirus disease
CRPD	Convention on the Rights of Persons with Disabilities
CSO	Civil Society Organization
CSSC	Christian Social Services Commission
ESC	Economic, Social and Cultural
ESCT	Emergency Social Cash Transfer Programme
HIV	Human Immunodeficiency Virus
HRC	Human Rights Commission
ICCPR	International Covenant on Civil and Political Rights
ICESCR	International Covenant on Economic, Social and Cultural Rights
IE	Independent Expert
IESCR	International Covenant on Economic, Social and Cultural rights
LNFOD	Lesotho National Federation of the Organizations of the Disabled
MHRC	Malawi Human Rights Commission
NAP	National Action Plan
NGDO	Non- Governmental Development Organisation
NGO	Non-Governmental Organisation
OHCHR	Office of the High Commissioner for Human Rights
PALOP	Países Africanos de Língua Oficial Portuguesa (Portuguese-speaking African countries)
PEPUDA	Promotion of Equality and Prevention of Unfair Discrimination Act
PIN	Personal Identification Number
PoA	Plan of Action
RAP	Regional Action Plan
SDGs	Sustainable Development Goals
SPF	Sun Protection Factor
SSHRC	Social Sciences and Humanities Research Council
UN	United Nations
UNESCO	United Nations Educational, Scientific and Cultural Organization
USD	United States Dollar
UV	Ultraviolet
ZIMAS	Zimbabwe Albino Association
ZWL	Zimbabwe Dollar

REGIONAL DIRECTOR'S FOREWORD

Albinism is a genetic condition that remains profoundly misunderstood in Africa. Furthermore, the social impact is far-reaching driven by the perpetuation of myths and misconceptions that lead to acts of aggression, discrimination, and other harmful behaviours towards those with the condition. Due to the general lack of awareness on albinism, the rights of persons with albinism are frequently violated. Persons with albinism face discrimination and stigma on account of their physical appearance resulting in social exclusion and barriers to accessing health, education and employment.

Globally, Amnesty International works to ensure greater equality and non-discrimination. In Southern Africa, our work in this area includes challenging inequality and discrimination against persons with albinism. This journal is part of our efforts to foster a greater understanding of the inequalities and discrimination that persons with albinism face in Southern Africa. It highlights the hurdles that persons with albinism face in accessing economic, social, and cultural rights, pays particular attention to the challenges persons with albinism faced in this regard during the Covid-19 pandemic and suggests remedies for addressing these issues.

I am grateful to Innocentia Mgijima-Konopi for her leadership and dedication in convening the authors and reviewers, ensuring contributions to this seminal initiative from a diverse group of people. Contributors who tell their stories, experiences and challenges faced by persons with albinism in Southern Africa in this volume include persons with albinism, mothers of children with albinism, academics who are also chief advocates, and members of civil society who work with and support persons with albinism in various countries across the region.

The authors' experiences and vast knowledge and expertise contributes immensely to the objective of achieving a deeper understanding of the inequalities experienced by persons with albinism as demonstrated by Busisiwe Mahlaba's story, a South African mother who fought bullying and exclusion of her 15-year-old son Sibusiso, who had refused to return to school after being bullied by a teacher resulting in teasing by his peers. Her's is a legacy of devotion and love for her son, one of her three children with albinism, for whom she fought to break down some of the barriers in her community, including discrimination, stigma, and access to education, before her untimely passing in August 2022.

The stories told by Thomas Mtonga, Esther Lungu, Kalisto Kalimaposo and Joseph Mandyata in their contribution are emblematic of findings in the 2010 Zambia Census which showed that out of the 15 000 persons with albinism of school-going age, only 37.3 per cent were at school, 37.5 per cent had dropped out and 25 per cent had never attended school. The authors found that some parents are concerned for the safety of their children and prevent them from going to school.

Margarida Ferreira Carneiro's case study of Derton Zabo, a child with albinism from Sofala Province, in Mozambique, who died in 2020 from skin cancer at the age of 15, illustrates that protective measures such as access to sunscreen should never be considered optional. Derton's case inspired the creation of Kanimambo, a Portuguese NGO by Margarida. One could argue that Derton may have received treatment sooner if he had not been forced to hide due to stigma and misconceptions which are rife in many African cultures including in Malawi, Mozambique, Zambia and Tanzania where albinism is considered a bad omen.

In many places some people falsely believe that body parts and tissues of persons with albinism such as hair, nails, and genitalia, have magical powers when used for ritual purposes and bring good fortune and healing. These misconceptions are highlighted in Flavia Pinto's story whose father's grave was vandalised and his body parts taken. Grave tempering crimes are predominantly observed at graves with remains of persons with albinism. Flavia formed AZEMAP as a memorial to her father. The evidence shows that other families face similar attacks, but most remain unsolved due to inadequate police investigation, allowing perpetrators to continue to target persons with albinism.

Submissions received by the Office of the High Commissioner for Human Rights in response to a call for input on the impact of the Covid-19 pandemic on persons with albinism and young people, expressed concerns about how persons with albinism have been scapegoated for the pandemic. The UN High Commissioner for Human Rights highlighted reports of persons with albinism being labelled 'Corona' or 'Covid-19' in an attempt to scapegoat them for the pandemic, practices which often incited brutal attacks against them.

Overall, the *Southern Africa journal on albinism and socio-economic rights* goes beyond highlighting the many tragic stories in the lives of persons with albinism, but also showcases interventions and offers recommendations for remedies, including condemning discrimination, debunking myths, enacting laws against hate crimes, and implementing inclusive measures for economic and social participation.

Amnesty International is indebted to the many contributors who have shared their stories and experiences in this volume and will continue to challenge inequality and discrimination in all its forms in the struggle for a world where human rights are enjoyed by all.

Tigere Chagutah
Amnesty International Regional Director
East and Southern Africa

FOREWORD BY THE UN INDEPENDENT EXPERT ON THE ENJOYMENT OF HUMAN RIGHTS BY PERSONS WITH ALBINISM

Ms Muluka Anne Miti Drummond

In 2022, I started my mandate as the second UN Independent Expert on the enjoyment of rights by persons with albinism. Prior to taking up my role, I had listened to many stories of persons with albinism regarding their life growing up and living as a person with albinism. In my role, I continue to hear these stories. Stories, like the ones in this journal, of resilience, strength and perseverance against the odds. Stories of love, support and activism by parents and families of persons with albinism and, quite importantly, activism by persons with albinism themselves. I think of a young girl I met in Madagascar recently who, despite the insistence of those around her that the local name for those with albinism was not derogatory, told a room full of adults that she did not like the term and wanted to be called by her name because that is who she is. A simple message, but a powerful message. Persons with albinism are people with personal names, dreams, strengths, as well as vulnerabilities.

Albinism is a rare, non-contagious, genetically inherited condition which commonly results in the lack of melanin pigment in the hair, skin and eyes, causing vulnerability to sun exposure. Those with albinism are often much lighter in complexion than the general population of the communities in which they live. A lack of understanding of the condition often leads to myths and superstitions about persons with albinism, which dehumanise them. As the stories in this journal illustrate, many are subjected to derogatory terms, bullied and ostracised. In some cases, the ill-treatment can be worse. I regularly receive reports of persons with albinism being abducted, mutilated for their body parts and sometimes killed. As Flavia points out in her story, the ill-treatment does not end at death. Graves of persons with albinism are desecrated and their body parts are taken.

I welcome this journal by Amnesty International, which sets out the challenges and achievements of persons with albinism. Through the personal stories in the journal, it challenges the way people dehumanise them, the callousness of ignorant teachers, cruelty of children and devastating impact of lack of awareness. At the same time, the articles set out the existing and growing laws and standards for the protection and promotion of the rights of persons with albinism. The journal shows that, while the physical attacks against persons with albinism must be urgently tackled, these are not the only violations of the rights of persons with albinism that states should be concerned about. Busisiwe, Diana and Masekara’s stories all show how what some people consider harmless teasing can impact the right to education. It’s even worse when this is carried out by those who should be carers and should know better. These stories exemplify how, without adequate support from the school, those who are different can be subjected to mental anguish that can potentially have a lasting impact.

As the article by Thomas Mtonga et al, on the role of families in the education of learners with albinism points out, ‘Education plays a transformative role in human development’. Without education, persons with albinism in Africa are more likely to end up in lower paying, outdoor jobs with an increased risk of skin cancer and less financial means to mitigate the negative effects of UV rays, or to fortify their lives against attacks. The article further highlights the pivotal role played by the family in ensuring the education of children with albinism. However, without the necessary support of the school and the state in eradicating the harmful myths and beliefs around albinism, the drop-out rate of persons with albinism will continue to be high. I therefore reiterate the recommendations of the mandate, echoed in this article, for the State to ensure public education to demystify albinism, as well as to ensure inclusive education policies for learners with albinism.

It is heart-warming to see the positive role played by family in the stories of Busisiwe, Diana and Masekara, but as the article by Thomas Mtonga et al illustrates, this is not always the experience of learners with albinism. Actions to support families of children with albinism, including social protection programmes and relevant sensitisation on the importance of education for children with albinism, are indispensable. Related to this, the particular role of mothers of children with albinism is shown in the article by Meghann Buyco et al, on access to healthcare by mothers impacted by albinism in South Africa. This article emphasises the importance of the provision of health education, awareness-raising, and advocacy in enhancing the ability of mothers and their children with albinism to enjoy their human rights.

While reading Diana’s story, I was struck by how people with disabilities, including albinism, are unfairly left out of participation in society due to a lack of sufficient knowledge on albinism and health education. With enough knowledge of skin cancer prevention, particularly the use of sunscreen, protective clothing and a big shady umbrella with appropriate UV protection, Diana would have been able to join her friends on the beach trip without the negative consequences of sunburn. Such stories remind us why it is important for authorities to consider albinism, and not just the visual impairment of persons with albinism, as a form of disability. (Dianah Msipa’s article on albinism as disability clearly explains this.) The stories remind us that, for persons with albinism, sunscreen and protective clothing are a form of assistive device. Furthermore, they remind us of the responsibility of States to put in place adequate measures for the participation of those with disabilities in society, including by ensuring reasonable accommodations and access to assistive devices for them. As Dianah Msipa alludes to in her article, ensuring measures are in place for active participation of persons with albinism is a matter of justice. This requires a human rights-based approach to disability to enable access to justice for the vindication of social, economic and cultural rights for persons with albinism. It would be remiss of me not to mention national action plans on albinism when referring to the protection of such rights. As exposed in the article by Sethu Mbuli-Robertson, such plans are holistic. They not only deal with attacks, but ensure specific measures for the advancement of all rights, including social, economic and cultural rights.

I hope the stories and articles in this journal will help all readers understand albinism and the experiences of those with albinism a little better. I hope they will encourage you as readers to seek out further information. Above all, I hope that some of the readers will be government officials who will be reminded of their obligations and motivated to ensure the rights of persons with albinism.

PREFACE

Albinism is a rare, non-contagious, genetically inherited condition present at birth. In almost all types of albinism, both parents must carry the gene for it to be passed on, even if they do not have albinism themselves. The condition is found in both sexes regardless of ethnicity and in all countries of the world. Albinism results in a lack of pigmentation (melanin) in the hair, skin and eyes, causing vulnerability to the sun and bright light. As a result, almost all persons with albinism are visually impaired and are prone to developing skin cancer. There is no cure for the absence of melanin that is central to albinism. The condition is profoundly misunderstood and mystified in many societies. The physical appearance of persons with albinism is often the object of erroneous beliefs and myths influenced by superstition. These beliefs have fostered acute marginalisation, social exclusion, and at times physical attacks against persons with albinism.

Whilst the human rights situation of persons with albinism in Southern Africa varies per country, certain challenges are common throughout the region. Persons with albinism encounter multiple and convergent barriers to the full enjoyment of their rights to health, education, and work, as well as challenges in accessing social services.

The journal which is the first publication of its kind focuses on the Economic, Social and Cultural Rights (ESC Rights) of persons with albinism in Southern Africa. It seeks to bring to prominence and foster a greater understanding of the inequalities and discrimination that persons with albinism in Southern Africa face in the realisation of their ESC rights, how these have been accentuated in the context of the Covid-19 pandemic, the impact thereof and recommendations to address the issues. The various articles written by activists, civil society organisations and scholars impacted by albinism reiterate the obligations of Southern African states to guarantee the full enjoyment of socio-economic rights of persons with albinism and their rights to equality and human dignity.

This volume features nine articles by Meghann Buyco, Dr. Sheryl Reimer-Kirkham, Dr. Barbara Astle, Dr. Maretha de Waal, Dr. Jennifer Kromberg, Nomasonto Mazibuko, Innocentia Mgijima-Konopi, Dr. Ramadimetja Shirley Mogale, Dianah Msipa, Emma Strobell, Dr. Bhekisisa Maxwell Thabethe, Mpho Tjope on access to healthcare by mothers impacted by albinism in South Africa; Chisomo Kaufulu on an intersectional feminist approach in advancing the reproductive health rights of women with albinism in Southern Africa; Maureen Mswela on scapegoating persons with albinism for the pandemic: deepening existing stigma; Dianah Msipa on recognising albinism as disability as the key to ensuring equal access to justice for the vindication of economic, social and cultural rights by persons with albinism in South Africa; Margarida Ferreira Carneiro on the plight of persons with albinism in Mozambique: The role and action of Kanimambo Organization in the struggle against inequality and discrimination; Aldridge Munyoro Covid-19 and the emerging health issues facing persons with albinism in Zimbabwe; Sethu Mbuli-Robertson on the role of National Action Plans in advancing the economic, social and cultural rights of persons with albinism in Southern Africa; Thomas Mtonga, Esther Lungu, Kalisto Kalimaposo, Joseph Mandyata on the role of families in the education of learners with albinism in Zambia; and Bonface Massah on the role of National Human Rights Institution in ensuring protection of economic social cultural rights of persons with albinism in Malawi.

The journal also contains personal narratives by Flavia Pinto, Rufaro Martin Chinyanga, Busisiwe Mahlaba, Diana Rose Leonard and Masekara Sekoankoetla.

The journal is quite an accomplishment. We are grateful to all those who contributed to the compilation of the journal particularly, the authors and reviewers, without whom this publication would not be possible. Your efforts and contributions have helped reaffirm how human rights are universal, indivisible, interdependent and interrelated regardless of race, nationality, or disability. We in particular acknowledge the contribution of the late Dr. Bhekisisa Maxwell Thabethe and Busisiwe Mahlaba who authored two of the articles in the journal. Their commitment to advancing the rights of persons with albinism in South Africa is immortalised in this journal.

We would like to thank our editors, Innocentia Mgijima-Konopi (convening editor), Patricia Lund, Ruusa Ntinda, and Satang Nabaneh, for their invaluable insight and expertise regarding the articles published in this journal. Your guidance was greatly appreciated.

We also thank Phillipa Kabali-Kagwa and Lawrence Hoba for their support in curating personal narratives that highlight the complexity and uniqueness of the experiences of persons with albinism across borders and generations. Kate Painting who did the language and style editing.

Lastly, we would like to thank our partner, the Ford Foundation, whose invaluable support enabled us to realise this journal.

ACCESS TO HEALTHCARE BY MOTHERS IMPACTED BY ALBINISM IN SOUTH AFRICA

Meghann Buyco, Dr. Sheryl Reimer-Kirkham, Dr. Barbara Astle, Dr. Maretha de Waal, Dr. Jennifer Kromberg, Nomasonto Mazibuko, Innocentia Mgijima-Konopi, Dr. Ramadimetja Shirley Mogale, Dianah Msipa, Emma Strobell, Dr Bhekisisa Maxwell Thabethe and Mpho Tjope

Abstract

Mothers impacted by albinism in Africa encounter extraordinary circumstances, both as mothers of children with albinism and mothers who themselves have albinism. Albinism is a non-contagious, recessive, genetic condition that causes a decrease or absence of melanin in the skin, hair, and eyes. Persons with albinism experience low vision and the risk of skin cancer because of this genetic condition. They also deal with discrimination and stigma on account of their physical difference. In certain regions, deeply rooted spiritual and cultural beliefs about evil and misfortune persist, such that persons with albinism are ostracised and excluded. Women and girls with albinism are particularly vulnerable to human rights violations because of social constructions of gender that enable multiple and intersecting forms of stigma, discrimination, violence, and inequality.

In this paper, we focus on access to healthcare by mothers impacted by albinism in South Africa, and the inequalities and discrimination experienced by them. As a research-advocacy-policy network with team members from six countries, we are conducting ethnographic research on mothering and human rights, including mothers who themselves have albinism or have children with albinism. The aim of this four-year study is to explore, through a human-rights lens, the resilience of mothers affected by albinism, at the intersection of gender, colourism, and religion, in Tanzania, South Africa, and Ghana. In this paper, we focus on South Africa, where we conducted virtual and in-person field work with mothers impacted by albinism and key stakeholders engaged in human-rights related work. We draw on these data to illuminate mothers' experiences in accessing healthcare. We apply a patient-centred access to health framework with the dimensions of: 1) Availability; 2) Affordability; 3) Accessibility; 4) Acceptability; and 5) Adequacy. Mothers continually face a complex array of societal and structural challenges in accessing healthcare, ranging from lack of evidence-informed care at the time of giving birth to an infant with albinism; lack of access to health information on how to care for an infant/child with

albinism; lack of access to genetic counselling; and inaccessibility of services including skin care and vision care, especially in rural locations where transportation may pose a challenge. Access to healthcare also involves the right to respectful, non-discriminatory care, given the stigma and discrimination faced by persons with albinism in the context of gender inequalities. We highlight how the social determinants of health profoundly impact access to healthcare, and the achievement of the Sustainable Development Goals (SDGs) to ensure the economic, social, and cultural rights of mothers impacted by albinism.

Photos used with permission from Patricia Willocq (2015) were obtained from the White Ebony Collection. Retrieved from patriciawillocq.com/white-ebony

Introduction

People are impacted by albinism worldwide in different ways, regardless of gender, race, or ethnicity.[1] Oculocutaneous Albinism Type 2 (OCA2), the most prevalent and visible type in the African context, is a rare, non-contagious, genetically inherited disease that causes a decrease or absence of melanin in the hair, skin, and eyes.[2] Thus, persons with albinism suffer from varying degrees of visual impairment and increased risk of skin damage due to sun exposure.[3] With the hot tropical climate, the Cancer Association of South Africa[4] has acknowledged that persons with albinism have the highest risk of developing skin cancer.[5,6] The prevalence of albinism in South Africa is at least 1 in 3 900, a rate that is amongst the highest in the world.[7] In certain regions in Africa, concerns have been raised due to the human rights violations experienced by persons with albinism on account of their physical differences.[8] They have been associated with erroneous beliefs and harmful witchcraft-related practices such as the belief that they are ghosts, cursed, or that their body parts could be used for ritual purposes to bring luck and fortune.[9] Women and girls impacted by albinism are particularly vulnerable due to social constructions of gender that further enable multiple and intersecting forms of stigma, discrimination, violence, and inequality.

In this paper, we draw on research in South Africa to focus on access to healthcare by mothers impacted by albinism (whether they have albinism themselves or have children with albinism). Although both parents must be carriers of a gene for albinism to conceive a child with the condition, mothers in the African context face inequalities and discrimination.[10] From birth, they face negative responses from their families or healthcare providers, which extends to child-rearing, seeking access to healthcare, and obtaining education about albinism.[11,12]

Background: Healthcare System in South Africa

The healthcare system in South Africa is two-tiered, with an under-resourced public health sector and a private sector that is mainly covered by private insurance or medical aid schemes that can be expensive.[13,14] Most people depend on public healthcare facilities for services provided by the government free of charge to everyone.[15] With half of the national health budget spent on public healthcare to serve the majority of the population, public healthcare services are characterised by shortages of staff, long waiting times, and inadequate equipment.[16,17] In addition, transportation costs to the clinics or hospitals are shouldered by the people and can be unaffordable.[18] Some people resort to walking to obtain services, resulting in a greater burden for people residing in rural areas. The access is further limited due to the impact of power cuts that result in equipment not working.[19] Social determinants of health, such as low education and poverty, amplify challenges relating to access to health services for persons with albinism.[20,21]

Methods

As a research-advocacy-policy network with team members from six countries (South Africa, Tanzania, Nigeria, Ghana, United Kingdom, and Canada), we are conducting a four-year ethnographic study (Funding: SSHRC, Canada #435-2019-1120) to explore through a human-rights lens the resilience of mothers affected by albinism, at the intersection of gender, colourism, and religion. Research ethics clearance was granted from four universities in Canada; Tanzania's National Institute of Medical Research and the Tanzania Commission for Science and Technology; and the University of Pretoria, South Africa.

We recruited participants through convenience and purposeful sampling (for a detailed description of the study methodology, see Reimer-Kirkham et al.).[22] The first phase in Tanzania included 62 participants: 26 mothers impacted by albinism and 36 key stakeholders. The second phase is in South Africa, which is the focus of this manuscript with our interim data. During the Covid-19 pandemic, we conducted virtual and in-person fieldwork with 22 mothers impacted by albinism and seven key stakeholders (including healthcare providers, an educator, a faith leader, and NGO staff) engaged in human-rights-related work. As in Tanzania, we employed semi-structured interviews, with the facilitation of community-based researchers and cultural liaisons in South Africa. Data management occurred with NVivo 12™ software and involved line-by-line coding which progressed through levels of abstraction to thematic analysis. We foreground the healthcare access experiences of mothers in South Africa, drawing on the Health Access Livelihood Framework (ACCESS) that features the dimensions of availability, affordability, accessibility, acceptability, and adequacy.[23] Three themes stand out in the narratives of our participants: accessing health-related services; attaining health literacy; and discrimination and stigma as preventing or negatively impacting health access.

Project Findings and Application of the Access Framework

Access to Health-related Services

The ability of mothers in our study to access health-related services is influenced by the availability, affordability, and accessibility of services.[24] These components include: physical accessibility, which talks to the location and infrastructure aspects; financial, which is about costs and economic-related issues; and delivery of services in a reasonable timeframe.[25] In South Africa, as in Tanzania, a shortage of dermatological, ophthalmological and optometry services results in the lack of skin cancer screening, vision testing, and treatment services. The waiting periods to access such services in public hospitals are quite lengthy with most rural populations being underserved as people often need to travel long distances to access services and qualified personnel. Anne*, a mother with albinism living in a rural area with limited access to healthcare resources, states that she can obtain free sunscreen from the hospital. However, she must walk each time because she does not have the funds for transportation. This places her at risk of violence/attacks and sun exposure. Nora*, a mother of a child with albinism who also lives in a rural setting, explains that when she ran out of sunscreen, she was turned down by her local hospital because she was not yet eligible since she came earlier than scheduled. She also expresses concern about the quality of the sunscreen given by the government, stating that 'it is not working … it's watery … it's terrible'. The sunscreen should have a high sun protection factor (SPF of 30 or higher) to provide adequate sun protection. In some instances, mothers must resort to buying sunscreens themselves, which can be expensive, especially for mothers who are unemployed. Nora also discloses challenges regarding accessing specialists, as there are long waiting periods to see the skin or vision specialists.

Health Literacy

For mothers in our study, health literacy is dependent upon access to health information and genetic counselling, especially prior to leaving the hospital after giving birth. This information is required to make mothers aware of available resources in the community, be better prepared when they come home, and overall improve the continuity and coordination of care. Mothers would not know what services are necessary if they do not know what their child with albinism may need. This concept, therefore, relates to availability or approachability, where people who are facing healthcare needs can perceive that there are existing services, that they can be reached, and recognise that access to those services has an impact on an individual's health.[26] The majority of the mothers in our study state that they are not provided with education about albinism on or after they gave birth. For instance, Adira* who lives in an urban area, states that she was unaware of the presence of genetic counsellors or social workers who could help her navigate through her new responsibilities. When she reflects on her first

*Pseudonym

day with her child with albinism, she remembers being unsure about how to take care of her child's skin: 'I had to bathe the child. I didn't know if I should use normal soap. I didn't know if I should put petroleum jelly on the skin of the baby, which I did because I didn't know what to do.' Only when her family member explained that her child needed sunscreen and protective clothing did Adira take it upon herself to find relevant information through a Google search. Without appropriate education on albinism, mothers are unaware of what resources to access and how to prevent sunburn, skin cancer, and additional vision problems. For mothers who had access to a genetic counselling clinic, they were referred by their attending doctor soon after they gave birth and were even connected to a dermatologist and eye doctor. Imani* lives in a major city in South Africa. She says she felt more confident raising her child after being given education about albinism and was able to explain the condition to her family that led to their acceptance of her child. She emphasises during her interview how important health education is for other mothers so that they would have the knowledge on how to take care of their child with albinism. Health literacy is also supported by albinism organisations, such as the Albinism Society of South Africa, that offer community education, advocacy, and service provision.[27]

*Pseudonym

Discrimination and Stigma

For mothers to experience the ACCESS framework's dimension of acceptability, the cultural and social factors that impact the experience must be acknowledged and understood.[28,29] In this context, the prevalent misconceptions or lack of knowledge about albinism by the community, including healthcare providers, lead to mothers experiencing discrimination and stigma that hinders them from accessing adequate healthcare. Some mothers, for instance, report rejection from clinics because they had a child with albinism. One nurse describes his experience assisting a mother to give birth to her baby with albinism. When the mother saw her baby, the nurse explains that:

> **“There wasn’t any sense of any happiness within her on her face. But the nurses present did not explain to her right away; instead, they talked among themselves before speaking with her, and then only said ‘oh it’s an albino’. When [the nurses] left the room, stories began to circulate.”**

The nurse explains that even healthcare professionals have misconceptions:

> **“Due to the knowledge that they have or the rumours that are being spoken by a number of people… some of them saw that this is a possibility that this child might be stolen or kidnapped … People are still killing these people and they’re doing muti with them.”**

In this example, the healthcare providers’ reactions as well as the heightened commotion resulting from seeing a baby with albinism distracted them from supporting the mother, causing her further distress. The response of the nurses and doctors influenced how the mother perceived the situation.

Mothers are impacted by how services are delivered or offered, displaying the need for adequacy of care.[30] An example from our study is Audrey*, who describes her birth experience in an urban city hospital where she had a caesarean section and was immediately separated from her child. The doctor had a face of worry, but she was not given any explanation until she was reunited with her baby with albinism. Her doctor explained albinism in a negative light: ‘These children are very sensitive … when compared to other children.’ Audrey did not appreciate how albinism was explained with the doctor’s inference that her baby was somehow inferior. She got annoyed, ‘because in my heart I understand albinism doesn’t matter.’ As a result, she perceives the interaction as a negative experience instead of a day of celebration. The need for mutual respect, sensitivity, and compassion at the point of care is crucial to shifting the power balance between healthcare providers and patients, through recognising the capacity of the mothers.

*Pseudonym

Discussion

Healthcare access frameworks[31,32] bring into focus the interface on the supply side of health services and the demand or user side of those accessing the services. Most mothers in our study reported a lack of access to health services, a lack of health information, and the impact of discrimination and stigma. Although albinism organisations provide some services, it is the national and provincial departments of health that hold the responsibility to provide health services. Clinics must refer patients to services so that they can receive the appropriate information and treatment. As a positive example of this, in South Africa's major city hospitals, genetic counselling clinics are available for referrals right after birth.[34] During the session, mothers will be counselled about the genetic cause of albinism, the risk of recurrence, the prognosis, how to manage the condition, and how to access the necessary specialist services. According to healthcare access frameworks, information accessibility directly provides comprehensive details to people about available services, and hence it can be seen as a cross-cutting component when issues of health accessibility are discussed. Indeed, insights from our various research projects reveal information accessibility as the cornerstone for mothers impacted by albinism. Recognising that health disparities are much greater in rural areas as many health services are often unavailable or difficult to reach,[35] parents can often be referred to well-informed representatives from various albinism associations for information and support in the community.

Most Southern African countries have not fully adopted an overall national strategy to strengthen the protection of the human rights of persons with albinism, including the right to health.[36] Though many of these countries have a national cancer strategy, skin cancer is not one of the priority areas. Some governments have added sunscreen lotions to their list of essential medicines for primary healthcare, making the product available and free of charge to persons with albinism. The need for further action is not only the responsibility of the healthcare system but also that of the general population among whom health awareness needs to be expanded, especially among those who are most vulnerable, so that capacity to use services is increased.[37]

Access to healthcare is commonly understood as a proximal social determinant of health, meaning that health outcomes are contingent upon healthcare access.[38] Moreover, because of their intersecting nature, other more distal determinants such as education, poverty, housing, and employment amplify limitations to health access. The findings underscore the need for a more upstream access to health itself, recognising the overlap in access at the health systems level, as well as at the level of the social determinants of health. As mothers tend to be the individuals taking the initiative to ensure access to health for their children,[39] measures to support mothers should be considered and prioritised. Access to healthcare also involves the right to respectful, non-discriminatory care, considering the discrimination, stigma, and negative community attitudes faced by mothers impacted by albinism. Drawing from the Sustainable Development Goals,[40] these mothers are among the women who need to be involved in decision-making regarding health issues and provided access not just to health services, but also to employment and economic benefits. Addressing poverty, unemployment, and limited access to health services would promote their ability to achieve a higher standard of living and quality of life for themselves and their children.

Limitations

The study limitations relate to the non-representativeness of the small sample size, and the inability to engage in extended fieldwork due to the Covid-19 pandemic.

Conclusion and Recommendations

Our research in South Africa reveals the important overlap in access to health services at the health systems level, as well as at the level of the social determinants of health. Although the South African health system possesses various structural challenges, the experience of mothers impacted by albinism is heightened by their unique circumstances due to discrimination and gendered inequities. The provision of health education, awareness-raising, and advocacy would enhance the ability of mothers and their children impacted by albinism to enjoy their human rights, particularly in accessing healthcare. The following recommendations are made towards this end.

Education for Health Professionals should address the importance of respectful, non-discriminatory care and health information for persons with albinism.

Governments must ensure access to health services for persons with albinism, including genetic clinics, skincare, and free sun lotion and vision screening. Mothers, in particular, must be supported in accessing health services for their children with albinism. Support should also be given to albinism associations for their continued community education and advocacy.

The authors comprise the South Africa research team which is part of a broader research team exploring the experiences of mothers impacted by albinism in the African Context. Led by ***Dr. Sheryl Reimer-Kirkham****,* ***Dr. Barbara Astle****, and* ***Ikponwosa Ero****, our team comes from diverse backgrounds including nurses, educators, genetic counsellor, and CSO/NGO activists. To read more, please visit our blog motheringandalbinism.com/.*

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BEING SBU'S MOM

Busisiwe Mahlaba

My name is Busisiwe Mahlaba, I am a mother of three and two of my children have albinism. This is the story of my son, Sbu.

Sibusiso is now a 15-year-old boy. When Sbu started going to primary school in Diepkloof, Soweto, he knew little about albinism. He was happy and had two friends, Sibusiso and Mpendulo. They all sat at the back of the class. I was so excited that my son was doing well until he got to second grade. We kept going even though I saw that his handwriting was bad. I just told myself that it'll improve because he's still in his lower grades. He had his glasses, so I had hope as well. Unfortunately, everything started to become a nightmare for Sbu. Whenever they wrote in class the teacher would look at his work and embarrass him. She would make fun of his handwriting and the other students would laugh at him.

At first, he kept quiet about this, then one evening he decided to tell me what went on in class. This didn't sit right with me, but I had to have a thick skin in front of him. I told him that he was going to be fine even though I knew that his writing was bad. At the back of my mind, I never thought a teacher would be so heartless and make fun of him in class. I decided to see the teacher the following morning. I observed she was an elderly woman and was very surprised that an elderly woman would behave in such a manner. I was hurt by this because we send our kids to school expecting teachers to protect and guide them as parents, but she was the one condoning the bullying.

I asked to have a meeting with her while Sbu went to class with other learners. Getting straight to the point, respectfully, I asked her why was she making fun of Sbu in class. I also asked her why he was seated at the back since he couldn't see the board properly.

'I thought Sbu could see properly because he has glasses on', she responded, adding that they sit taller students at the back and shorter ones in front.

'I make fun of all the kids in class, not only Sbu', she added.

I then asked her to please seat him in front because he is visually impaired and to never make fun of him in class because it is not his fault. I then gave more info about albinism. It surprised me that she knew nothing about albinism and yet she was a qualified teacher. We came to an understanding that he would be given extra time when he wrote since the board was blurry. She also promised to have some work written on paper and more to be done verbally.

I was grateful for this and thought everything would be back to normal. Then, one day at work the phone rang. It was the school. The very same teacher called saying she's been trying to get some kids to stop bullying Sbu but they won't stop. She asked if I could quickly come and assist, I immediately asked for permission to leave work and rush to the school. On the way out I phoned Mama Nomasonto Mazibuko, whom I had seen on the internet when I Googled albinism. She is the founder of an organisation for persons with Albinism. I was lucky to get her online and told the story the teacher shared and that I had been called to calm the situation. She advised me to go to the school and get the whole story. She then gave me a number of the office in the Johannesburg CBD and ask for the team to assist.

I rushed to the school, I was late, the children had already been released. Fortunately, the teacher was still in her class, so I asked her what happened. She told me that five boys were bullying Sbu at break-time and telling him that he was white and must go and attend school with the whites. I asked her where these students were. I was very angry. She told me they had already left but they were told to bring their parents along for a meeting and disciplinary action. I was so angry that if I had seen those kids, I don't know what would have happened.

I went home very heartbroken asking myself how I was going to face my boy. When I got home, he wasn't there, he had gone to the grandparents. I quickly followed him there and while walking I dialled the office Mama Sonto (Nomasonto) had advised me to contact. Thembi answered. I gave her an outline of the story; she was touched and said she would accompany me to the school, she was such a kind lady.

As I reached the granny's house, I didn't know what to say or do. The grandparents had however already made it easier by calming the situation, the boy was playing with his toys as if nothing had happened on that day. When I asked him if he was okay out of motherly concern, he answered and said, 'I don't want to go back to school again'. I was crying and agreed just to appease him. Granny told me to rest since I had a long day.

The next morning, I met Thembi and shared the whole story. She insisted on seeing Sbu before we went to the school just to have a little session with him which turned out well because he was willing to go back to school again but only if Thembi joined. Later we went to the parents meeting, unfortunately they were not there. Thembi and I sat down with the principal and the teacher and decided to have an awareness session about albinism at the school. Two days later we were back at the school, Thembi, two guys who have albinism, and myself. The children had their usual morning at the assembly right after their morning prayer. The awareness started. It was fun, people asked questions and some teachers even confessed that they knew little about albinism. The session helped, Sbu was the hero of the day.

This awareness made a huge difference and made me happy because I knew it did not only help Sbu but other kids that would attend the school after Sbu.

***Busisiwe Mahlaba** was a mother of three kids – Sipho, Sibusiso and Luna. Two of her children Sibusiso and Luna have albinism. Busisiwe passed away following a sudden illness in August 2022. She was a passionate advocate for the rights of her children and others with albinism. At the time of her passing she was a community liaison for the Mothering and Albinism project in which she interviewed mothers of children with albinism about their experiences giving birth to a child with albinism and accessing healthcare services.*

SCAPEGOATING PERSONS WITH ALBINISM FOR THE PANDEMIC: DEEPENING EXISTING STIGMA

Maureen Mswela

Abstract

In light of the Covid-19 pandemic, this paper presents a logical extension of my previous work on the plight of persons with albinism in Africa. Prior to the Covid-19 crisis, persons with albinism were known to be experiencing a number of human rights abuses and violations, but with the advent of the pandemic, it has been reported that their situation has been exacerbated in several ways, as with other marginalised groups.[1] The Covid-19 pandemic was accompanied by yet another dimension of stigma against persons with albinism by causing what can be described as an upsurge of discriminatory practices against this group of people. Despite the World Health Organization's firm caution not to identify the pandemic with a geographical location, people, ethnic groups, or even animals, in several countries persons with albinism have been branded with names such as 'Corona' and 'Covid-19', scapegoating them for the pandemic and further fuelling existing stigma.[2] Along with the unfounded fear that persons with albinism are responsible for the pandemic, verbal and physical attacks on persons with albinism were reported to be increasing during the peak of the pandemic.

In 2020, a governmental statement released by the South African Deputy Minister in the Presidency for Women, Youth and Persons with Disabilities indicates that persons with albinism have been negatively labelled as 'Corona' or 'Covid-19' in an attempt to scapegoat them for the pandemic.[3] Similar concerns were echoed in 2021, on International Albinism Awareness Day, by the United Nations Commissioner for Human Rights, Michelle Bachelete, who highlighted that in some countries persons with albinism are smeared with names such as 'Corona' and 'Covid-19' further fuelling existing stigma and ostracising them in their communities.[4] The Justice for All Human Rights Journal is an additional window of information which has reported that persons with albinism have been negatively associated with the spread of the contagion.[5] Remarks springing from the aforementioned journal, indicate that persons with albinism in various regions in South Africa have become scapegoats for the pandemic and have been labelled as 'Corona' for the reason that the virus originated in China where the majority of the population is light skinned.[6]

Submissions received by the United Nations Office of the High Commissioner for Human Rights (OHCHR), in response to a call for input on the impact of the Covid-19 pandemic on persons with albinism and young people, express concerns about how persons with albinism have been scapegoated for the pandemic.[7] The submissions received by the UN(OHCHR), came from among other stakeholder groups; comprising

organisations with community networks that are working to prevent, document, and respond to violence against persons with albinism and have robust and visible grassroots activists.[8] Of particular relevance, are the submissions from the Albinism Foundation of Zambia and the Alive Albinism Initiative of Zimbabwe which noted how persons with albinism have been associated with the spread of the pandemic and how anti-albinism sentiments and derogatory statements have been permeating in public during the pandemic in Zambia and Zimbabwe.[9] In Zimbabwe, this resulted in persons with albinism avoiding moving around during the pandemic, thereby restricting their freedom of movement.[10] In Zimbabwe, many persons with albinism are reported to have feared the development of additional myths, such as that sleeping with a person with albinism could cure the disease or that their body parts could be used in vaccines.

Similarly, from a media perspective, existing news portals and social networking services, such as the Business Insider, the Daily Maverick, Africa Daily, and Twitter, suggest that persons with albinism have been victims of blame for the pandemic, although this information is framed in a very general manner without any comprehensive details on the discriminatory behaviours.[11] The absence of formal studies and data detailing the extent of scapegoating of persons with albinism for the pandemic in Southern Africa and Africa in general, poses a key challenge to scholars with an interest in issues affecting persons with albinism to consider undertaking studies that will present the first systematic evidence concerning the extent of scapegoating persons with albinism for the pandemic.

With a focus on the Southern African Region, yet equally acknowledging the global crisis of


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human rights violations of persons with albinism, this paper attempts to advance an understanding of why persons with albinism are targets of blame during a pandemic. This contribution makes use of the scapegoat theory to build an analytical framework that illustrates how and why scapegoating is a typical human response to situations of heightened medical uncertainty. The paper examines how the long-standing pre-pandemic understanding of albinism has an influence on blaming this group of people for the Covid-19 pandemic. Important intersections are drawn between scapegoating, hate speech and hate crimes. I consider a foundational debate concerning the meaning of a hate crime within the context of everyday lives of persons with albinism during the pandemic. Hate crimes and hate speech are two well recognised and exceedingly prioritised human rights phenomena, yet, the idea of relating the two phenomena to scapegoating has received scant scholarly attention in the context of albinism. The social consequences of hate crimes, which include, stigma, isolation and discrimination are flagged, and an argument is advanced on the impact of stigma, isolation and discrimination on the enjoyment of socio-economic rights by persons with albinism during the pandemic.

The Scapegoat Theory

In contemporary times, the term ‘scapegoat’ has found application in much broader contexts. It has been increasingly used as a metaphor to refer to an innocent person or a group of people who shoulder the blame of perceived problems, negative outcomes, or any wrongdoing.

Scholars who have focused on understanding the scapegoat theory in social psychology, describe scapegoating as a displacement and channelisation of blame, resentment, anger, anguish and frustration towards a convenient social target, with the purpose of reducing uncertainty during a period of threat.[12] The scapegoaters seek to symbolically eliminate their own feelings of fear by perceiving a targeted person or a group of people as dangerous or immoral and therefore banishing, segregating, or punishing the victim.[13]

Placing the blame on vulnerable targets is said to retrieve a sense of control and certainty amongst the scapegoaters as they obtain a clear explanation for an outwardly incomprehensible and undesirable outcome which is hard to explain or control. Referring to Gordon Allport, a founding figure of personality psychology, Rothschild, states that scapegoating is a flexible strategy for preserving the perceived moral value of oneself, by projecting superficially unrelated negative characteristics onto scapegoats.[14]

Experiencing sickness or any other threatening yet unpredictable force that lacks a straightforward explanation or controllable cause may drive people to explain the major threat in a manner that restores perceived control. This way, the scapegoaters feel hopeful instead of seeing a threatening event as an unpredictable force.[15] Through this response, the scapegoaters make sense and comprehend their physical and social environment. Displacement of blame helps the scapegoaters to maintain that the outward world is stable, predictable and orderly and not threatening or dangerous.[16] In concurrence with the scapegoat theory, we observe Freud’s theory of displacement which is a defence mechanism observed when feelings of frustration and anger are taken out on individuals, groups of people or even objects.[17]

Under a pandemic siege, distressed citizens will try to explain the devastating number of deaths in diverse ways. Such explanations range from mere observations to political and economic opinions; some citizens fall back on stereotypical opinions about ethnic groups, superstitions and inexplicable theories, cultural and social practices, while others try to understand the catastrophe through the lens of long-standing prejudices. Focusing on syphilis, largely in Italy, William Eamon asserted that ‘new diseases bring out a culture’s deepest phobias’.[18] He further asserted that, ‘outbreaks of new diseases, especially epidemics, are striking visual affirmations of something gone terribly wrong in the wider social sphere. Because new diseases place severe strains on a culture, testing its ability to assimilate novelty’.[19] The effectiveness of scapegoating rests on pre-existing belief systems in the culture. It is understood that the socio-cultural standing of the victim(s) in society are effective justification tools that serve to authorise resentment towards the scapegoats. Myths and stereotypes deeply rooted in culture tend to signal the social groups that are likely to be suitable targets for discharging frustration or blame.[20]

I have more fully explored, elsewhere, the understanding of albinism from an African context and for the purposes of this discussion it is worth briefly revisiting how albinism has been understood pre-Covid-19 in Southern Africa.[21]

Racialisation of Covid-19: A Threat to Racial Minorities

From a cultural belief perspective, albinism has always been erroneously understood to be a contagious curse from the gods and scapegoating persons with albinism for Covid-19 is simply another way of perpetuating an existing myth.[22] Despite its known clinical aspects, albinism is further portrayed as the cause of an illness, infection, or a virus that needs to be cured in order to rescue nations. Through blaming persons with albinism for the pandemic, albinism is portrayed as a major threat to the world; a scapegoat for a pandemic that has endangered the global health.

Rather than understanding albinism from a genetic or biological perspective, it has been understood as a bad omen or punishment from ancestors to atone for the wrongs of the past.[23] Consequently, being in contact with a person with albinism is believed to cause bad luck, sickness, or even death. The existence of some diseases or illnesses in some Southern African communities and in Africa in general, is understood far from the clinical diagnosis.[24] Disease or illness has repeatedly been understood as being caused by attacks coming from evil or bad spirits, whereas others identify illness or disease as an atonement for angering the ancestors.[25]

In Zambia and Zimbabwe respectively, anti-albinism sentiments permeating in public during the pandemic included derogatory statements such as: ‘You are the ones who brought Covid-19 here’ or ‘You are not needed here in our country because you are the same people bringing Covid-19 here’.[26] And: ‘I was in the passenger seat, we were passing through a high-density suburb, some kids were on the street, and they started calling me Covid because I have albinism. They were running after the car, saying look at Covid.’[27]

In Ghana, during the start of the pandemic, a conspiracy theory made the rounds that the Covid-19 pandemic, ‘originated in China; anyone who looked Caucasian including young persons with albinism was a carrier’.[28]

From the narration above, one deduces a sense of fear of persons perceived to be 'foreign' or 'strange'. The lightness that differentiates persons with albinism from other black Africans, construes persons with albinism as carriers of what is wrongly perceived as the 'China virus', for the reason that the pandemic originated in China, where people have fair skin, and consequently persons with albinism are perceived as carriers of this disease. This is another dimension of the stigma attached to albinism during the pandemic.[29]

Persons with albinism do not identify in looks with their racial group and it is the colour of their skin that points to negative social constructions. Without a sound understanding of the clinical aspects of albinism it is difficult to comprehend their identity. Where views on colour are the basis for differential treatment, such discrimination is specifically called colourism. Colourism functions both intra-racially and inter-racially. Intra-racial colour discrimination arises when an affiliate of a particular racial group makes a distinction on the basis of skin colour between members of their own race.

As they battle existing social and cultural challenges, persons with albinism are confronted with a new wave of marginalisation related to the Covid-19 pandemic. Albinism has traditionally been shrouded in myths, stereotypes and dangerous yet erroneous cultural beliefs. Most, if not all, of these beliefs are wrong and very harmful to the emotional, physical and psychological wellbeing of persons with albinism. Albinism is also mystified in popular culture, with persons with albinism often depicted as figures of evil. This portrayal forms the backdrop against which the scapegoating of persons with albinism can be understood, and for this reason, this discussion has briefly alluded to some of these erroneous beliefs.

Effects of Victimisation of Persons with Albinism as Scapegoats during the Covid-19 Crisis

The Office of the High Commissioner for Human Rights (OHCHR) has since noted that, blaming persons with albinism for the pandemic stimulates or rather incites brutal attacks against them. Killings and attacks of persons with albinism are said to have increased during the pandemic. A report by the OHCHR links the Covid-19 pandemic to harmful practices impacting persons with albinism. The belief that an individual has mystic powers that allows them to cause harm or damage to other persons or things, repeatedly leads to accusations of witchcraft. This often results in attacks on the accused and/or their family.[30]

The pandemic has elevated the risks of persons with albinism to hate crimes. Crimes driven by intolerance towards other people are termed hate crimes. By standards of international human rights law, hate crimes are motivated in whole or in part by an offender's bias against a race, religion, disability, sexual orientation, ethnicity, gender or gender identity.[31] For a crime to constitute a hate crime, it should be committed out of bias motivation. Three elements must be met for a successful action against perpetrators of hate crimes. A prejudicial motive is the critical identifying element of a hate crime. The intent of the perpetrator must be clear and there should be an underlying criminal offence.

An argument is also advanced that the terminology used to describe persons with albinism is both intra-racially racist and xenophobic since it promotes anti-albinism and anti-Asian bias and exclusion, and it is such language that is likely to increase the risk of hate crimes.

Scapegoating as a response to Covid-19 results in ostracism and stigma. Stigma is generally seen as a deeply discrediting or disgracing attribute which at the same time reduces the victim from a normal person to a tainted, discounted one. Reaction to scapegoating will obviously vary on a person-to-person basis. Some persons with albinism might not be affected by scapegoating while others might be negatively affected by stigma. Persons with albinism, as the victimised group, are positioned apart from the normal social structure, with such separation implying devaluing the other. The effect of othering on persons with albinism has been recognised as a strong factor which may have a bearing on their self-esteem and social identity within their families and the broader society.[32]

Refusal to seek medical attention and various other socio-economic services due to the fear induced construction that persons with albinism are a threat of contagion is a reality. Stigma can lead to denial in seeking Covid-19 testing and seeking clinical care where a diagnosis has been made. This way, persons with albinism are positioned at the peripheries in the fight against the pandemic. They exclude themselves in the broader efforts to combat the spread of the Coronavirus as they are erroneously feared to be contagious. When society responds to a pandemic by stigmatising minority groups, it fails to build strategic coalitions for preventing the spread of virus. The ‘scapegoats’ isolate themselves from the community and this affects the overall quality of their life. The stigma attached to albinism is a social construct, which has a significant socio-economic impact on the lives of persons with albinism. Stigma leads to prejudice and such prejudice in most cases leads to active discrimination directed toward the victims.

Conclusions and Recommendations

This contribution calls for policy debates on the need for legislation that will condemn bias motivated crimes against persons with albinism in Southern Africa. Integral to the necessity of legislation on hate crimes, is that such legislation will aid governments to gather more accurate statistics involving hate crimes, especially noting that there is currently no official crime category for hate crimes. This submission is in harmony with the current UN Independent Expert on Albinism’s submission that specific laws protecting persons with albinism against hate crimes, will condemn bias motive against persons with albinism, prompt further investigations and impact on the way victims are treated.[33]

Acknowledging that there have been a handful of organisations of persons with albinism in Southern Africa who have initiated campaigns to debunk myths in partnership with governments, this contribution continues to challenge policy makers, non-profit organisations, social activists, persons with albinism, and the communities at large to continue to debunk myths that surround albinism and the Covid-19 pandemic.

International Albinism Awareness Day, an annual event on 13 June, is a powerful advocacy tool which can be used as a springboard for raising awareness on misinformation and disinformation around albinism and Covid-19.

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THE PLIGHT OF PERSONS WITH ALBINISM IN MOZAMBIQUE: THE ROLE AND ACTION OF KANIMAMBO ORGANISATION IN THE STRUGGLE AGAINST INEQUALITY AND DISCRIMINATION

Margarida Ferreira Carneiro

Abstract

There has been little written about albinism in Mozambique. This piece provides insight into the position of those with albinism in this country through the case study of Derton Zabo, a child with albinism from Sofala Province who died in 2020 from skin cancer at the age of 15. It is also an account of how one person can make a difference, in starting an organisation and working with local stakeholders to alleviate the various barriers faced by those with albinism in affected communities. The piece draws heavily on my personal experience as a volunteer and president of Kanimambo, a Portuguese Non-Governmental Development Organisation (NGDO) created to tackle the inequality and discrimination experienced by persons with albinism in the country and concludes with recommendations to alleviate some of the barriers faced by those with albinism discussed in the case study.

Derton Termo Zabo

As a physical disability, albinism alters appearance (by colour differentiation) and constrains the ability to concentrate and learn (by visual limitation). It generates a state of extreme physical vulnerability that puts its bearers' lives at risk, either by their exposure to the sun or by their exposure to society itself. It is a condition that causes profound psychological damage due to fear and discrimination experienced by those affected, causing them to seek invisibility within their communities. The daily life of many persons with albinism remains difficult despite the existence of several legal instruments in Mozambique that guarantee the rights of persons with albinism on an equal basis with others.[1]

Such is the case of Derton Zabo, a young boy whose life story is a paradigmatic example of the difficulties experienced by persons with albinism in Mozambique, which I will now recount. I first met Derton in 2009 when he was just four-years-old. He lived in Gorongosa, a village in a rural district in Sofala Province, which is located in the Central-Eastern part of Mozambique. According to the most recent Census,[2] the village has a population of 177 000 individuals that predominantly work in agriculture, live in houses built of reeds, corrugated iron or rubble and plaster and have access to water mainly from the nearby river and wells.[3] The use of petroleum, kerosene and firewood is their main source of energy and less than one per cent of the population has access to the internet with radio being the prevalent means of access to information.

Derton lived the first few years of his life confined to the backyard of his home due to his parents' fear that his different appearance would draw risky and threatening attention on him from the community. He was never taken to a hospital and as a result, had no clinical diagnosis of his albinism. Not having sufficient information to understand that albinism is a hereditary condition, his parents, farmers who only knew how to sign their names, deduced that their child was a 'work of magic'. Culturally in many parts of the country, the birth of a child with albinism is considered a bad omen for the family and the entire community. This is because, on the one hand, persons with albinism are thought of as supernatural beings who are associated with occult forces and thus perceived to be a cause of bad luck, illness, or death. There are reports of babies with albinism that were killed at birth by their own parents or taken to spiritual leaders to be disposed of.[4] On the other hand, persons with albinism are also, in some communities, considered as a source of healing, purification and power.[5] Both these myths endanger the lives of this group leading to their persecution, physical attacks, mutilation and killings.

Being aware of these beliefs and practices, Derton's parents chose to keep him hidden. In a fortuitous coincidence, when he was five a nurse at the Chitengo Clinic and the Gorongosa National Park Mobile Health Clinic asked Derton's brothers how many siblings they had. From the answer, it became clear that one of the siblings had never been to the clinic. The nurse, upon following up with a home visit to the family, discovered Derton. She was able to educate his parents about his condition as well as his sensitivity to the sun and his visual problems. He was able to get access to medical care and treatment for his sunburns and wounds on his skin. In time, and with the appropriate follow-up, Derton was growing up healthy and enjoying school.

Having a post-graduate degree in Sociology, my interest in issues associated with albinism began from a very early stage of my academic career. It was a subject that particularly moved me in the field of Anthropology. Due to my family origins, I decided to carry out research on Mozambique. At the time, little or no literature existed on albinism in this country.

During one of my inquiries, I got in touch with Vasco Galante, Director of Communication at the Gorongosa National Park. Over the course of several months, he sent me daily clippings from Mozambican newspapers reporting kidnappings and assassinations of persons with albinism that were taking place in this country. The more I researched this issue, the more it felt I needed to act. It was during this period I learnt about Derton.

In 2012 I asked Vasco Galante to grant me access to the community where Derton's family lived so that I could provide them with sunscreen, inaccessible to the majority of the population, who struggle daily to survive the conditions of poverty in which they live. In October, I travelled to their village with my sister, where we were allowed to take part in the communities' daily life, religious celebrations and, of course, to meet Derton, to whom we offered sunscreen.

Upon returning to Portugal, I shared this impactful experience with close friends and in a short period of time Kanimambo was born. We immediately started gathering sunscreens, sunglasses, hats and appropriate clothing. Those in our network who could carry these in their suitcases when travelling to Mozambique and ensure their delivery to the Gorongosa National Park did so. From then, Derton, as well as many others, began to receive sunscreen and school supplies. Derton always thanked us with a shy and somewhat confused and incredulous smile.

I was fortunate to be able to follow Derton's growth. Equipped with the necessary means to alleviate his visual impairment, and adequate sun protection (ophthalmologist-prescribed glasses, sunscreen, hats, long-sleeved shirts and trousers), he was fully integrated into his community and achieving academic success in school. In addition, the approach taken by Derton's teachers was also pivotal. The understanding that he should be seated in the front row of the classroom and away from the windows, where the sun streams in, amongst other adjustments, ensured an inclusive and informed approach to his needs which was crucial to his well-being and ability to focus. The teacher's positive approach also ensured that his classmates would realise that, however different, Derton was just like them.

Two years ago, in 2020, Derton was diagnosed with a malignant tumour in his neck. For five months, messages and phone calls were frequently exchanged, in order to share information between associations committed to seeking the best care for him. Over the course of five months, both in Portugal and in Mozambique, I worked intensively with medical volunteers, Gorongosa National Park teams, and the MAssaLA Association (Associação de Médicos no Abraço a Moçambique, a Mozambican NGDO) to get Derton and his father from his village to the central hospitals in Beira and then Maputo, so that he could undergo urgent surgery.

Despite all our efforts, the tumour spread very quickly, and at the age of 15, his greatest enemy – the sun – robbed him of his future. Derton passed away, leaving a testimony of courage and of urgency to make communities and the world aware of the plight of persons with albinism in Mozambique.

Kanimambo, NGDO

Derton inspired the founding of Kanimambo. Today we provide services to around 400 persons with albinism in Nampula, Maputo, Inharrime and Gorongosa. We operate thanks to private donations and the generous volunteerism of our members in Portugal and in Mozambique. Our activities are based on four vectors of action: 1) Education/Awareness; 2) Distribution of means of protection; 3) Health; and 4) Integration. Our main course of action is to collaborate with Mozambican local associations and government through the establishment of partnerships, thus enabling us to obtain the necessary authorisations and support for medical missions (ophthalmology and dermatology) in which persons with albinism are diagnosed and treated, provided with graduate glasses with UV protection, sunscreen and healing creams, hats and clothes. More recently we are supporting unemployed persons with albinism to obtain work positions that are both dignified and adjusted to their special needs.

Since our founding, which celebrates a decade this year, we have carried out multiple institutional, medical (ophthalmology and dermatology), and educational missions. We are also one of the organisations that is most engaged in creating initiatives as part of the commemorations of International Albinism Awareness Day (June 13), from its establishment by the United Nations in 2014. Attacks on persons with albinism continue to be an issue of grave concern. The Multi-sectoral Action Plan on Albinism, which was adopted on 24 November 2015 by the Mozambican Council of Ministers clearly addresses this critical issue but continuous awareness raising is needed to address the root cause of the attacks.

Awareness-raising activities are constant. Due to the efforts of our team of volunteers, we have engaged with several Mozambican Ministers, with the President of the Republic of Mozambique, Filipe Nyusi (2018), with the Secretary General

Photo credit: Domingos Muala. Nurse Antonia from Gorongosa National Park expressing gratitude to the Kanimambo team for delivering sunscreen, hats and sunglasses to the park residents.

of the United Nations, António Guterres (in which we were accompanied by several local albinism associations – 2019) and with the President of the Portuguese Republic Marcelo Rebello de Sousa during his official visit to Mozambique (2019).

As already alluded to, there are little data available on this subject in Mozambique. Our goal is to provide information based on our experience in the field, to convey the actual reality experienced by persons with albinism in this country. We are proud to have been able to provide information to the 'Report of the Independent Expert on the Enjoyment of Human Rights by Persons with Albinism on her Mission to Mozambique' in 2016 which led to extensive recommendations for action for persons with albinism.

We also participated with Ms Ikponwosa Ero (former UN Independent Expert on Albinism) in the Conference on Capacity Building on Albinism in the PALOP (an acronym for 'Portuguese Speaking African Countries') in 2019. On 13 June 2022, we organised a conference that brought together representatives from Mozambique, Angola, and Guinea-Bissau associations, as well as the current Independent Expert, Ms Muluka-Anne Miti-Drummond.

Overcoming the Challenges

I reflect on three approaches that Kanimambo has successfully used to address some of the challenges highlighted by Derton's case and others that can be adopted by different stakeholders. Awareness and advocacy are a paramount and core part of the approach. The empowerment of local organisations is also essential to ensure that they act in a direct and sustained way to change the paradigm.

Promoting Healthcare and Everyday (Informed) Habits

In direct relation to article 25(1) of the Universal Declaration of Human Rights, article 89 of the Constitution of the Mozambican Republic (Health) establishes that 'all citizens have the right to medical and sanitary assistance, according to the law, as well as the duty to promote and defend public health'. Article 116 further stipulates 'medical and health care for citizens shall be organized through a national health system, which shall benefit all Mozambican people … [and] the State shall promote the expansion of medical and health care and equal access of all citizens to the enjoyment of this right'. Moreover, article 16 of the African Charter on Human and Peoples' Rights also states that: '1. Every individual shall have the right to enjoy the best attainable state of physical and mental health; 2. State Parties to the present Charter shall take the necessary measures to protect the health of their people and to ensure that they receive medical attention when they are sick.'[7]

For persons with albinism, exposure to the sun presents the greatest threat to their health. The reduction of melanin means that their natural shield against ultra-violet rays A and B is weakened, leading to painful damage to the skin and, in severe cases, cancer, often with fatal outcomes. Access to means of protection is still scarce. Economic difficulties or misinformation regarding the good practices towards their use are the two main causes. In a country known for its high temperatures, the use of hats, long-sleeved shirts and shoes that cover the feet is not a simple or comfortable practice, even when its positive impact is considered.

The daily application of sunscreens as a protection routine still falls short in terms of general implementation and understanding. There are cases in which sunscreens are applied at night, as they are considered a fragrant cosmetic accessory.

Vision problems are another serious aspect of the health problems caused by albinism. The lack of visual acuity, nystagmus and strabismus, hinders the ability to read and understand subjects in school. Given the discriminatory nature towards persons with albinism, there are many cases in which students (among the few who can attend school) with albinism sit at tables located at the back of the room, therefore further away from the board. Even though in some cases access to ophthalmology consultations is provided, the cost of acquiring corrective eyewear and sunglasses with UV protection is prohibitive for many communities that live in absolute poverty.

Aware this right has not been fully fulfilled in the context of persons with albinism, Kanimambo has been working to create multi-sectorial partnerships to provide access to healthcare information, services and products for persons with albinism. An example of this is the Medical Clinic project in Nampula in which the Portuguese Society of Dermatology, Maputo and Nampula Central Hospitals, the Provincial Government of Nampula, Lúrio University and Kanimambo are providing dermatological and ophthalmological services to persons with albinism in Nampula.

Promoting Education, Social Integration and Safety

In line with article 26 of the Universal Declaration of Human Rights, article 88 of the Constitution of the Mozambican Republic (Right to Education) establishes that: ‘1. In the Republic of Mozambique, education shall be a right and a duty of every citizen; 2. The State shall promote the extension of education to continuing vocational training and the equal access of all citizens to the enjoyment of this right’.[8] Article 17 of the African Charter on Human and Peoples’ Rights also states that: ‘1. Every individual shall have the right to education; 2. Every individual may freely take part in the cultural life of his community; 3. The promotion and protection of morals and traditional values recognized by the community shall be the duty of the State.’[9]

The right to education for students with albinism can be undermined by factors such as bullying, unprepared teachers, lack of inclusion aids, and insecurity. Such factors have a direct impact on school dropouts. Teachers are a vital key in promoting the full inclusion of students with albinism in the classroom, ensuring that they can sit away from windows and close to the blackboards and be allowed to use hats inside the classroom if needed.[10] Teachers are able to ensure pedagogical materials are provided in larger print for students with albinism and can play an active role towards the usage of inclusive speech to foster positive attitude towards students with albinism. Kanimambo submitted in 2018 a project for the insertion of two pages about albinism in the national textbooks, an important step towards fostering inclusive education for this group. The proposal was taken into consideration by the Mozambican government, but its implementation has yet to be carried out.

Promoting Fulfilled and Independent Persons with Albinism

The right to work is stipulated in article 23 of the Universal Declaration of Human Rights,[11] as well as in article 88 of the Constitution of the Republic of Mozambique: ‘1. Work is a right and a duty of every citizen; 2. Every citizen has the right to a free choice of profession…’

Discrimination hinders the principle of equality in professional achievement. Awareness sessions in companies should encourage employers to hire persons with albinism on equal terms. However, the understanding that persons with albinism should work indoors, where there is no sun exposure is critical. By engaging in civic education practices,the organisation produces and distributes free brochures, flyers, reports, news and instructional posters, and organises seminars, lectures and conferences on albinism. One of the results of these actions was the celebration of a protocol with the Mozambican Security Association, which saw the employment of two persons with albinism in 2021. Being aware of the distinct characteristics of their condition, this association has taken the precaution of assigning them duties as receptionists or CCTV security guards, asserting that the job market in this area of security is not lacking in opportunities for employability suitable for persons with albinism.

Conclusion

Lack of understanding about albinism can have fatal consequences. Many persons with albinism in Mozambique continue to face multiple and intersecting forms of discrimination including in accessing education and healthcare. It is in the hands of each one of us to take action. It only takes one person to start a movement.

Margarida Ferreira Carneiro *is the founder and President of the NGDO Kanimambo – Association of Support to Albinism. Dedicating herself to the issue of albinism for a decade, she has managed to build a cohesive team that assists more than 400 persons with albinism. Her organisation has been received by the Presidents of Mozambique and Portugal, as well as by the Secretary-General of the United Nations, in a constant effort to raise awareness of this cause in close work with local associations in Mozambique.*

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ZEMA, LOVE BEYOND LIFE: THE STORY OF MY FATHER

Flavia Pinto

Darkness Descends

José Manuel Francisco Otolino de Sousa Pinto is my father's full name. Born on 15 May 1962, in Mozambique, he had albinism. My father was one of the most complete human beings I have ever met – charismatic, selfless, and a very present father – my best friend and confidant. He was an activist and worked for Caritas – an organisation that took care of marginalised people. He did this in his work, for the community and his family. He died on 15 July 2015, from diabetes.

I miss him every day.

After he died, we decided to start an organisation to honour him, and to continue doing his work. We called it the Associação Zé Manuel Pinto – AZEMAP for short. The aim of AZEMAP is to support persons with albinism. Now, around this time there was a wave of violence against persons with albinism. It was believed to have started in Tanzania, then spread to Malawi and later to Nampula, in Mozambique. It was terrible, not even the dead were spared! From Nampula it spread to Angónia, and then to Tete, where we were.

Grieving Again

A week before the first anniversary of my father's death, unknown individuals vandalised his grave, removed the coffin, and took parts of his body. According to the coroner's report they took the bones of both his arms and legs. This event left the whole family in fear and panic. We were devastated! I keep asking myself: 'Why all this evil? What did these people do with my father's bones?' We followed up with the police to try and trace the crime, but we did not have much success. I was not happy with the police investigations. There was no follow up.

I felt so angry and helpless.

I thought that maybe if I studied law, I would know what to do – how to talk to the police and the courts. From 2017 to 2021, I enrolled to study for a Degree in Legal Sciences (Law) at the Politécnica University in Tete. This training in law helped me to read cases, to help our beneficiaries put cases together, and to follow up in the courts. These studies, and AZEMAP are what helped me as I grieved for my father twice – his death, and the desecration of his grave.

AZEMAP – Retracing my Father’s Footsteps

We registered AZEMAP in February 2016 and held the first General Assembly in March 2016. AZEMAP has permission from the government to work in 15 districts in Tete. We integrate people in families, we take children to school – paying school fees, giving them materials for school and uniforms too. We help persons with albinism care for their skin and protect themselves from cancer. Every month we send them sunscreen. We have focal points in each district – resource people in the community that help us do their work. They are often either teachers, doctors, nurses, and other reliable points of contact. We believe in the dignity of work and so we help families start businesses by giving them access to training so that they can start. We teach them human rights. We have connections with police, prosecutors, and other links to support our legal actions.

AZEMAP works directly with the Province of Tete’s attorney. Fortunately, we have received positive support. I am not a lawyer yet. I’m still a jurist, but next year (2023) I’m going to take my bar exams to get a license to be a lawyer. Right now, my knowledge of the law helps me to understand, and help people understand what is going on. I can follow up and give input into the process. AZEMAP has a qualified lawyer to go to court, but I help put the cases together.

A Light in the Darkness

With the Association I have helped many people. But adopting a child has been the most powerful thing that has happened to me. I was never going to have children – that was not my plan. I started the Association, and I was just going to be an activist. I was very depressed at the time – I was grieving. With the police case looking into the desecration of my father’s grave not really moving, my life felt very dark. That was when Elisio came into my life.

In 2017 I received a call from the police. There were two parents who had been arrested as they were trying to sell a child with albinism. The child, who was two years and eight months old needed to be cared for while the parents were in jail, and their case was being heard in court. So, I took him in – because this was one of the things we do at AZEMAP. When I first met Elisio, it was as if we recognised each other. He came straight to me and gave me a big hug. On that day I felt something change in me – I had a deeper sense of purpose.

The outcome of the case was the father was convicted and is serving a prison sentence. The mother pleaded innocence and was released but she did not come to fetch Elisio. It was hoped that his grandmother would take him in, but in 2018 Elisio's grandmother wrote a letter to the court saying that she could not take care of Elisio. She said that he could be adopted. By this time, I was very devoted to Elisio and so we followed the legal channels for adoption. In 2020 the judge gave me the preliminary adoption papers. This gave me the opportunity to get documentation for him – birth certificates and the like – so that he could go to school. Now he is in school. Because I do not have the full adoption, he still has his parents' name. The parents have permission to visit but have not done so.

Elisio helped me come out of my depression, and I helped him find a family. We saved each other. I felt as if my father had sent him to me. We have been together for five years. He is a very good boy. He has taught me to be a mother. I am trying to be the best mother for him.

Looking back, I am grateful for my father's teachings. I am privileged and honoured to be his daughter and to have had the opportunity to live with him for 31 years. I will always celebrate the works of my father; I will honour his name. And most of all, I will love him forever! I believe he is protecting me, lighting my way so that I have wisdom and discernment, to take AZEMAP to reach all persons with albinism in Tete, Mozambique, in Africa and elsewhere in the world.

I have a tattoo with these words to demonstrate my affection and love for him.

Sonia Flavia Ferrão Pinto (Flavia Pinto) *holds an Economics and Administrative Management and Legal Sciences degree. She is the second daughter of José Manuel Francisco Otolino de Sousa Pinto who had albinism. She is also a mother to an 8-year-old boy with albinism. Flavia's father passed away in July 2015. After his death, she founded the association Ze Manuel Pinto AZEMAP, in his honour. She has been the president of AZEMAP for the last 5 years championing the rights of persons with albinism. Flavia does this work with a lot of love and a keen awareness of the lived realities of persons with albinism. She is committed to continuing to help the families of persons with albinism to live without fear.*

ALBINISM AS DISABILITY: THE KEY TO ENSURING EQUAL ACCESS TO JUSTICE FOR THE VINDICATION OF ECONOMIC, SOCIAL AND CULTURAL RIGHTS BY PERSONS WITH ALBINISM IN SOUTH AFRICA

Dianah Msipa

Abstract

Economic, social and cultural rights are enshrined in various legal instruments at the global, regional and domestic levels. The International Covenant on Economic, Social and Cultural Rights (ICESCR) is the primary instrument protecting these rights at global level whilst the African Charter on Human and Peoples' Rights (ACHPR) enunciates these rights at regional level. South Africa ratified the ICESCR on 12 January 2015 and ACHPR on 9 July 1996.[1] At domestic level, the Constitution of the Republic of South Africa, 1996 provides for a number of economic, social and cultural rights including housing;[2] healthcare, food, water and social security;[3] education;[4] language and culture;[5] and cultural, religious and linguistic communities.[6] In spite of the existence of these legislative frameworks, the denial of economic, social and cultural rights for persons with albinism persists. This makes the right to access justice for purposes of vindicating economic, social and cultural rights of paramount importance.

The right to access justice is distinct in that it is endowed with a dual character as both a right in, and of itself, and as a vehicle for the realisation of all other human rights. The justice system, along with its legislative, policy and institutional frameworks, exists to vindicate individual rights and freedoms, making the ability to access that system a necessary pre-requisite for the realisation of economic, social and cultural rights by persons with albinism in South Africa.

This article explores ways to improve equal access to justice by persons with albinism for purposes of vindicating economic, social and cultural rights in South Africa. Specifically, the article interrogates the merits of incorporating albinism into the definition of disability in South Africa, arguing that this may improve access to justice. In support of this contention, two arguments are advanced. First, because the dominant human rights approach to disability lends itself to increased access to justice, classifying persons with albinism as persons with disabilities would improve such access. Second, South Africa has a robust legislative framework for protecting the economic, social and cultural rights of persons with disabilities and persons with albinism can only benefit from these frameworks if albinism is incorporated into the identity category of 'disability'.

Is Albinism a Disability?

Albinism is a non-contagious inherited genetic condition that affects the production of melanin, resulting in the reduction or elimination of pigmentation in the skin, hair and eyes.[7] As a result, persons with albinism experience visual impairment, and weakened natural defences against the harmful effects of the sun, including skin cancer.[8] The crucial question of whether albinism is a disability must be addressed prior to examining the merits of such a classification. There are different approaches to this issue at global, regional and domestic levels. At the global level, the Convention on the Rights of Persons with Disabilities (CRPD) does not expressly include albinism in the non-exhaustive list of disabilities provided in article 1. Nevertheless, the Committee on the Rights of Persons with Disabilities (CRPD Committee) confirmed that albinism is a disability in *X v United Republic of Tanzania (X Case)*.[9] In 2017, the CRPD Committee presided over a communication brought against Tanzania by Mr X, a Tanzanian farmer with albinism. The author of the communication was attacked by two strangers who cut off his left arm.[10] After failing to obtain local remedies in Tanzania, Mr X brought a communication before the Committee alleging that his right to non-discrimination under article 5 of the CRPD had been violated. His claim was that he was discriminated against on the basis that he is a person with albinism, and since he considers albinism to be a disability, this constitutes disability discrimination.[11] Crucially, the CRPD Committee agreed with Mr X and found that he had been a victim of direct discrimination on the basis of disability in contravention of article 5 of the CRPD.[12] This indicates that the Committee accepted that albinism was a disability. Moreover, the CRPD Committee consistently referred to albinism as a disability in its concluding observations on the report submitted by South Africa.[13]

The CRPD's failure to include albinism in the list of disabilities outlined in article 1 was not detrimental for three reasons. First, the list of disabilities in article 1 of the CRPD is not exhaustive. Article 1 states that '[p]ersons with disabilities *include* those who have long-term physical, mental, intellectual or sensory impairments' (emphasis added). The use of the term 'include' is an indication that the list is not exhaustive. Second, the CRPD acknowledges that disability is an evolving concept.[14] As such, it is capable of accommodating more impairments that are not currently recognised as disabilities. Finally, though the CRPD does not provide a definition for the term 'disability', it does provide parameters to be met when considering what constitutes disability. The CRPD provides that disability results from the 'interaction between *persons with impairments* and *attitudinal and environmental barriers that hinders their full and effective participation* in society on an equal basis with others'.[15] Persons with albinism have an impairment and face numerous attitudinal and environmental barriers that hinder their full and effective participation in society. Therefore, they can be classified as persons with disabilities.

There is a similar approach to this issue at the regional level. The Protocol to the African Charter on Human and Peoples' Rights on the Rights of Persons with Disabilities in Africa (African Disability Protocol) considers albinism a disability.[16] The African Disability Protocol contains provisions that are relevant to albinism, indicating that albinism is recognised as a disability. In its preamble, the African Disability Protocol expresses alarm at the 'maiming and killing of persons with albinism in many parts of the continent'. Moreover, in article 1, the African Disability Protocol makes reference to harmful practices, which 'include behavior, attitudes and practices based on tradition, culture, religion, superstition or other reasons, which negatively affect the human rights and fundamental freedoms of persons with disabilities or perpetuate discrimination'. Article 1 of the Protocol also defines the pertinent practice of 'ritual killings' as the 'killing of persons motivated by cultural, religious or superstitious beliefs that the use of a body or a body part has medicinal value, possesses supernatural powers and brings good luck, prosperity and protection to the killer'. Article 11 of the African Disability Protocol deals with harmful practices, requiring member states to 'offer appropriate support and assistance to victims of harmful practice' and to 'eliminate harmful practices perpetrated on persons with disabilities'. Many of the ritual killings and harmful practices that are referred to here have been perpetrated against persons with albinism in many parts of Africa. Although the African Disability Protocol is not yet in force because it has not yet received the required 15 ratifications to bring it into force, it remains a part of the African human rights system since its adoption by the African Union in 2018.[17]

The position at domestic level is quite distinct from that at the global and regional levels. In South Africa, persons with albinism generally associate themselves with persons with disabilities because of the discrimination that both groups face.[18] For example, the report of the Independent Expert on the Enjoyment of Human Rights by Persons with Albinism on her visit to South Africa consistently refers to albinism as a disability.[19] Nevertheless, there is ambiguity in South African laws and policies about whether albinism is a disability.[20] Although South Africa's White Paper on the Rights of Persons with Disabilities does not expressly state that albinism is a disability, this is implied. Speaking about the violence and abuse to which persons with disabilities are often subjected, the White Paper includes persons with albinism, stating that: '[p]erceived or actual impairments associated with harmful traditional beliefs, such as albinism, are often associated with hate speech, ostracisation and even human trafficking and murder'.[21] In contrast, the Ekurhuleni Metropolitan Municipality's Policy Guidelines for People with Disabilities states that even though persons with albinism associate themselves with persons with disabilities, they are in fact not persons with disabilities per se.[22] This ambiguity is exacerbated by the fact that albinism is not expressly recognised as a disability in South African legislation and policies. The situation is the same in a number of other African countries including Ghana, Rwanda, Mozambique, and Zimbabwe. Consequently, persons with albinism cannot benefit from the protections afforded to persons with disabilities at domestic level.

A Human Rights Approach as a Prerequisite to Effective Access to Justice

Effective access to justice for the vindication of economic, social and cultural rights requires the adoption of a human rights approach. Over time, the disability rights movement has succeeded in significantly shifting perceptions and approaches to disability. The oldest model of disability, known as the moral or religious model of disability existed prior to the 1800s and has since been abandoned as outdated.[23] According to this model, disability was perceived as a punishment from God for the sins of the person with a disability or his or her parents or ancestors.[24] Because disability was seen as an act of God, the role that society played in disabling people with impairments was not recognised.

In the mid-1800s, the moral or religious model of disability was gradually replaced by the medical model of disability, which came about as a result of scientific advances that led to a better understanding of impairments.[25] The medical model perceived disability as inherent in the individual with impairment. In other words, having an impairment meant that one was disabled. In contrast with the moral or religious model, which did not envision any intervention, the medical model conceived of intervention in the form of a cure or rehabilitation to adjust the individual with a disability to their environment.[26]

In the 1960s and 1970s the social model of disability was developed. According to the social model, disability is a socially constructed disadvantage that is attributed to an environment that takes little or no account of persons with disabilities.[27] Disability arises at the point of interaction between a person with impairment and attitudinal and environmental barriers. Having an impairment on its own does not make one disabled. Because the social model of disability takes into account the impact of the external environment, it is capable of responding to the societal barriers that disadvantage people with impairments. The appropriate intervention therefore, involves making changes to the external environment in response to the person's internal needs.

The rapidly developing human rights model of disability perceives disability as a human rights issue. Persons with disabilities are regarded as holders of human rights and fundamental freedoms with a right to act in order to exercise those rights. The human rights model shifts the focus from the concept of disability to policy response to disability. Lawson opines that the human rights model 'can be viewed not as a model of disability, but as a model of disability policy'.[28] Unlike the descriptive nature of the social model which serves to describe the concept of disability, the human rights model is prescriptive and 'answers the question "what should we do" to advance social justice for disabled people'?[29] The answer to this question is always the advancement of disability law and policy reform in line with human rights principles set out in the CRPD.[30]

Such a human rights approach is crucial for the right to access justice. Because the focus is on responding adequately and appropriately through law and policy, the human rights approach is conceptually capable of driving the changes that are required in law and policy to ensure respect for economic, social and cultural rights. Such changes would address, through the law, barriers to equal access to justice faced by persons with albinism including attitudinal barriers and lack of access to information. However, a human rights approach is not usually applied to persons with albinism.

Generally, albinism is not well understood in Africa, allowing the survival of myths, misconceptions and superstitions. For instance, albinism is perceived as contagious and as a curse from God. Persons with albinism are considered sub-humans who do not die but simply disappear. Moreover, it is erroneously believed that having sexual intercourse with a woman with albinism can cure infertility and HIV and AIDS. The body parts of persons with albinism are thought to possess supernatural powers capable of conferring great wealth when used in witchcraft potions.[31] These misconceptions have resulted in an upsurge in attacks, mutilations and killings of persons with albinism for ritual purposes in about 27 African countries, including in South Africa. Children with albinism are targeted because it is relatively easier to abduct them and it is believed that their 'innocence' increases the potency of the potions.[32] Albinism is, therefore, perceived as a curse. This resonates with the outdated religious model of disability. Because albinism is viewed as a curse, the role that society plays in disadvantaging persons with albinism is often not considered. Improving access to justice for the vindication of the economic, social and cultural rights of persons with albinism is not usually at the forefront of many minds.

Moreover, albinism is generally perceived as a medical issue rather than a human rights issue. Albinism affects the production of melanin, resulting in the reduction or elimination of pigmentation in the skin, hair and eyes. As a result, persons with albinism experience visual impairment, and weakened natural defences against the harmful effects of the sun, including skin cancer.[33] Because persons with albinism require the use of vision devices, and, due to the threat of skin cancer, require the consistent application of sunscreen and limited exposure to direct sunlight, albinism is often perceived as a medical issue similar to the outdated medical model of disability.[34] As the medical approach only conceives of intervention in the form of a medical cure or rehabilitation, to the exclusion of any interventions targeting societal attitudes and behaviour, it is conceptually incapable of empowering persons with albinism.

In recent years, albinism has received greater attention at the global and regional level as a human rights issue, marking a gradual shift from viewing albinism solely as a health issue. For instance, in 2013, the United Nations Human Rights Council adopted a resolution on the prevention of discrimination and violence against persons with albinism. In 2015, the UN Human Rights Council introduced the mandate of the Independent Expert on the Enjoyment of Human Rights and Fundamental Freedoms by Persons with Albinism, tasked with monitoring the human rights situation of persons with albinism. These developments mark the beginning of a gradual shift towards a human rights approach. Nevertheless, disability rights activists have succeeded in popularising a human rights approach to disability to a greater extent than albinism activists. Classifying albinism as a disability may therefore be an advantage, as adopting a human rights approach to disability would serve to reconceive persons with albinism as rights holders who are entitled to act in order to exercise their rights.

Classifying Albinism as Disability is Necessary for the Enjoyment of Legal Protection

Section 9 of the South African Constitution prohibits discrimination on several grounds including race and colour. The Committee on the Elimination of Racial Discrimination has recognised that racial discrimination can occur along the lines of colour, even amongst people belonging to the same race, descent, national and ethnic origin.[35] The Committee therefore, acknowledged that persons with albinism face racial discrimination on the ground of colour.[36] Accordingly, persons with albinism can access equality protection on the grounds of race and colour.

Nevertheless, including albinism within the definition of disability would afford persons with albinism additional protection provided to persons with disabilities in the existing South African legislative, policy and institutional frameworks. Disability is included in a number of legislation, including the South African Constitution, the Employment Equity Act, and the Promotion of Equality and Prevention of Unfair Discrimination Act (PEPUDA).

The Constitution provides for the right to equality, which entails the 'full and equal enjoyment of all rights and freedoms', including economic, social and cultural rights.[37] Section 9(3) of the Constitution specifically prohibits unfair discrimination on various grounds including disability. Therefore, any unfair discrimination based on disability that may hinder persons with disabilities from enjoying the economic, social and cultural rights enshrined in the Constitution is unlawful. In order to ensure that persons with disabilities can vindicate their rights, the Constitution provides for the right to access courts. Section 34 of the Constitution states that '[e]veryone has the right to have any dispute that can be resolved by the application of law decided in a fair public hearing before a court or, where appropriate, another independent and impartial tribunal or forum'. Moreover, section 9 of the Constitution provides for the enactment of legislative and other measures to promote the achievement of equality.

To that end, PEPUDA was formulated in 2000 to give effect to section 9 of the Constitution and ensure that unfair discrimination does not occur in relation to various rights including economic, social and cultural rights.[38] Section 9 of PEPUDA deals with the prohibition of unfair discrimination on the ground of disability. It stipulates that persons with disabilities may not be denied any support or facility necessary for functioning in society.[39] PEPUDA also mandates adherence to the South African Bureau of Standards' regulations governing environmental accessibility[40] and stipulates that the failure to remove obstacles, or take steps to reasonably accommodate persons with disabilities is

Photo credit: Sowetan live. Thokozani Msibi, Knowledge Mhlanga and Brilliant Mkhize appearing at the Middleburg magistrates' court in South Africa for the murder of a teenager with albinism, Gabisile Shabane, 13 discriminatory.[41] Section 28 of PEPUDA provides for special measures to promote equality with regard to race, gender and disability. Where it is proved that unfair discrimination on the ground of disability was a factor in the commission of an offence, this qualifies as an aggravating circumstance for sentencing purposes.[42] In recognition of the fact that situations in which persons with disabilities may be unfairly discriminated against, PEPUDA includes access to justice as one of its guiding principles.[43]

Crucially, PEPUDA creates a key institutional framework in the form of equality courts that are established in accordance with chapter 4 (sections 16–23) of PEPUDA. The function of equality courts is to determine whether unfair discrimination, hate speech, or harassment have taken place.[44] Every High Court in South Africa is an Equality Court for the area of its jurisdiction.[45] Furthermore, the Minister may designate one or more magistrates' courts as equality courts for the relevant administrative region.[46] All orders made by equality courts have the same effect as an order made in a civil court.[47]

In the realm of employment, the Employment Equity Act is an important law that seeks to promote equity in the workplace.[48] More importantly, the Act protects persons with disabilities by prohibiting unfair discrimination on the grounds of disability.[49]

The policy framework in South Africa also provides further protection to persons with disabilities in relation to the enjoyment of economic, social and cultural rights. The White Paper on the Rights of Persons with Disabilities 'integrates obligations in the UNCRPD and responds to the Continental Plan of Action for the African Decade of Persons with Disabilities'.[50] Economic, social and cultural rights are included in the White Paper.[51] The White Paper also recognises the importance of access to justice in '[p]rotecting the right of persons at risk of compounded marginalization'.[52] Cumulatively, these legislative, policy and institutional frameworks are capable of affording a significant amount of protection of the economic, social and cultural rights of persons with disabilities in South Africa. However, in order for persons with albinism to enjoy these protections, the law needs to expressly include albinism within the definition of disability.

Conclusion

There is a need to align South African laws and policies with international standards that regard albinism as a disability. The CRPD Committee in its concluding observations on the report submitted by South Africa as well as in its communication in X v *United Republic of Tanzania*, clearly recognises albinism as a disability. Similarly, the Independent Expert's report on her visit to South Africa consistently refers to albinism as a disability. The current ambiguity relating to whether albinism is a disability has negative consequences in that it may prevent persons with albinism from accessing the legal protections afforded to persons with disabilities. Even though some of these protections can be accessed under the prohibition of discrimination on the basis of colour, recognition as persons with disabilities brings added benefits. For example, the human rights approach that has been developed in relation to disability is particularly important for access to justice for the vindication of economic, social and cultural rights.

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COVID-19 AND THE EMERGING HEALTH ISSUES FACING PERSONS WITH ALBINISM IN ZIMBABWE

Aldridge Tafadzwa Munyoro

Abstract

The Covid-19 pandemic exposed huge inequalities across the globe. As governments focus their attention on mitigating the effects of the pandemic, socio-economic and health rights of those groups that are already marginalised have taken a back seat. The paper advances the argument that in Zimbabwe the impact of this pandemic is much greater for persons with albinism because of their susceptibility to diseases such as skin cancer. This article further contends that the Covid-19 pandemic has amplified the health and socio-economic challenges of this group. The health and well-being of persons with albinism is now more precarious than ever. Therefore, government and civil societies need to collaboratively hasten policy responses to circumvent the health challenges faced by persons with albinism. To support this discussion, this author closely examines the current state of persons with albinism in Zimbabwe during Covid-19 by contextualising albinism in Zimbabwe. Secondly, an analysis is provided of two disability-related measures introduced by the Zimbabwean government to provide a social security safety net for persons with albinism. The paper also analyses potential health issues emerging for this population in the wake of the Covid-19 pandemic. Finally, the paper will draw on the case of Agnes, a woman with albinism, to show the intersections between Covid-19, health, albinism, and livelihoods that amplify the negative health experiences of persons with albinism during the Covid-19 pandemic.

Albinism in the Zimbabwean Context

Albinism is a condition that has always been associated with stigmatising discourses in Zimbabwe. Dominant discourses about persons with albinism represent this group as malevolent beings purposed to destroy communities.[1] There is a paucity of literature about the historical developments of the lives of persons with albinism in Zimbabwe. What is known from oral tradition is that persons with albinism used to be killed at birth because albinism was seen as a curse from the Gods.[2] It was believed that allowing a child with albinism to live was an abomination that would bring the wrath of the Gods upon the whole community. These killings were hidden from society because of the perceived disgracefulness of the birth. Though this practice seems to have disappeared, there is still suspicion that the infanticide of children with albinism continues in secrecy in some rural parts of Zimbabwe.[3,4] There are no reliable statistics about the number of persons with albinism in Zimbabwe, however, findings from Zimbabwe's Ministry of Health 'Living Conditions among Persons with Disability: Key Findings Report' estimate that over 3 900 people have albinism in Zimbabwe. This estimate is based on the 179 households that were surveyed for that report.[5]

Constitutional, Legislative and Policy Framework in Zimbabwe

The legislative framework underpinning the rights of persons with albinism in Zimbabwe is the Constitution of Zimbabwe Amendment Act 20 of 2013. The following sections and other national laws, statutes and policies are relevant:

- Section 30 provides for the rights to social security and social care;
- Section 48 guarantees the right to life;
- Section 49 guarantees the right to personal liberty;
- Section 51 provides for the right to human dignity;
- Section 52 provides for the right to personal security;
- Section 56 provides for equality and non-discrimination;
- Section 76 and 29 guarantees the right to healthcare; and
- Section 83 guarantees the rights of persons with disabilities;

Despite being protected by the Constitution the rights of persons with albinism continue to be undermined in part by the fact that the legal instrument concerned with the protection of the rights of persons with disabilities, The Disabled Persons Act 1992 of Zimbabwe is not clear on the position of whether albinism is considered a disability by law. This act only recognises the visual impairment related to albinism. The Disabled Persons Act defines a person with a disability as:

> **A person with a physical, mental, or sensory disability, including a visual, hearing or speech functional disability, which gives rise to physical, cultural or social barriers inhibiting him from participating at an equal level with other members of society in activities, undertakings or fields of employment that are open to other members of society.**

Photo Credit: Global Press Journal. Child wears long-sleeved clothing in Harare, Zimbabwe to protect her arms from sunlight. Retrieved at globalpressjournal.com

Such a definition is problematic because it reduces albinism to visual impairment only. In Zimbabwe, such a definition has led to the systemic exclusion of persons with albinism because health needs related to the skin are not prioritised. Apart from the visual impairment, persons with albinism have skin sensitivity and they need access to sun protection and other albinism-related services. However, such needs are not recognised, only visual needs are prioritised. Hence the persistent call by civil society for albinism to be acknowledged as a disability beyond the visual impairment. The United States Embassy's 2020 Human Rights Report on Zimbabwe highlights that Non-Governmental Organisations in Zimbabwe continue to lobby for the government to broaden the legal definition of disability to include disabilities such as albinism and epilepsy.[6] The current definition falls short in capturing albinism as a unique disability and this can potentially impede persons with albinism from fully enjoying their Human Rights.

Covid-19-Related Social Protection Measures for Persons with Albinism in Zimbabwe

Emergency Social Cash Transfer Programme (ESCT)

Like many governments across the globe, the Covid-19 pandemic caught Zimbabwe by surprise and policy responses toward vulnerable groups were quite slow. People with disabilities suffered greatly during the early days of the pandemic. Currently, there are no specific policy initiatives targeted at persons with albinism. However, key informants in government and civil society revealed that persons with albinism have benefitted from two measures introduced by the government as a way to reduce the socio-economic burden of Covid-19 on vulnerable households in Zimbabwe. One of the measures introduced by the government of Zimbabwe was the Emergency Social Cash Transfer Programme (ESCT) which was announced in 2020. Through this policy initiative, the government disbursed an estimated ZWL 2.4 billion (USD 7 454 400) targeting people with disabilities, the elderly, pregnant women, children under two years of age and child-headed households.[7] Through this policy initiative, people with disabilities can register their name and NetOne sim card at their local Social Welfare Department to receive ZWL 300, approximately USD 3.6/per month.[8] This policy initiative has the potential to improve the health outcomes of persons with albinism in Zimbabwe if scaled up. The initiative is crucial to mitigating the health and socio-economic challenges of persons with albinism during Covid-19. This disbursement can potentially assist persons with albinism to sustain themselves and also take care of their health needs. However, some scholars and activists have raised concerns that the ZWL 300 is not enough to cater for one's basic needs considering the ever-increasing cost of living in Zimbabwe.[9] Also, it is not clear how many persons with albinism benefitted from this policy. Drawing from past experiences, government policies do not always reflect the reality on the ground. Anecdotal accounts show that many persons with albinism have not received these social protection grants.

US$50 Facility

Another policy initiative introduced by the government of Zimbabwe during Covid-19 was the US$50 Facility. This policy initiative afforded all people with disabilities easy access to purchase foreign currency at financial institutions using standard bank rates. Zimbabwe is a multi-currency country. Initially, this facility was introduced to help the general population access foreign currency for domestic and other small purchases. The government of Zimbabwe later refined this policy to cater to people with disabilities, pensioners, the elderly, and those in need of foreign currency for health purposes.[10] In Zimbabwe, the most prominent currencies are the Zimbabwean Bond and the United States dollar. The United States dollar is very scarce and is mostly obtained from Forex traders on the black market. The exchange rates on the black market are extremely high, making the US dollar inaccessible to the public. Most people in Zimbabwe are paid using the Zimbabwean bond currency. In banks, the United States dollar is also scarce. Most shops and private health service providers prefer the United States dollar because of the continued devaluing of the Zimbabwean bond. Therefore, it is difficult to access health services if one does not have the United States dollar. In theory, this policy initiative was crucial to enable persons with albinism to access much-needed health services during Covid-19 because of easy access to United State dollars. However, data is still sketchy on how many persons with albinism benefitted from this policy. Also, research shows that persons with albinism are among the poorest in Zimbabwe. Many of them are not employed because of stigma and discrimination.[11] One can therefore argue that many of them may not be able to use this US$50 facility because they cannot afford to buy foreign currency, even with the cheapest rates. Hence, they are likely to continue having challenges in accessing health and other services during the Covid-19 pandemic.

Mandatory Hand Sanitising a Health Dilemma for Persons with Albinism: The Case of Agnes

There have been widespread reports that hand sanitisers available on the market cause irritation to the skin of persons with albinism. A report by the United Nations Educational, Scientific and Cultural Organization (UNESCO) brings to light the claims that local sanitisers are causing skin irritation for persons with albinism and they are developing patches on their hands because of these sanitisers.[12] Across the globe, countries have adopted mandatory sanitising of hands to try and curb the spread of Covid-19. In Zimbabwe, public facilities are required to sanitise all those that utilise these facilities.[13] Though these measures are noble and meant to protect the health of the general population, concerns have been raised by organisations of persons with albinism about the potential harm of these sanitisers on the skin of persons with albinism.[14] Despite these concerns, they are still required to sanitise before using public facilities. This potentially affects not only their health but also their access to basic goods and services.

The Zimbabwe Mail reported a story about Agnes, a 35-year-old woman with albinism, who was denied access to a supermarket after refusing to use the sanitiser provided, stating that her skin 'seriously reacts to sanitisers'. Her suggestion of washing her hands with soap and water was rejected and the management offered to get someone else to do her shopping while she waited outside. This was unacceptable to Agnes as it would mean giving her bank card and PIN to a stranger.[15]


Photo: © LAWILINK/Amnesty International

The case of Agnes is not an isolated case. The case provides an example of the socio-economic and health impact of some of the Covid-19 regulations on persons with albinism in Zimbabwe. Since the onset of Covid-19, there have been widespread reports about the potential harm of local sanitisers on persons with albinism.[16] What makes this concern more serious is the mandatory hand sanitising that has been adopted by many businesses across Zimbabwe.

It must be noted that there is no scientific evidence suggesting that sanitisers affect the skin of persons with albinism, this is an area of concern that future research needs to focus on to address these claims. In the case of Agnes, there is a huge intersection between health and socio-economic issues during Covid-19. A report by the Zimbabwe Human Rights Commission shows that persons with albinism are struggling to access public facilities because of the mandatory sanitising measure.[17] According to this report:

> **"The fact that skins of some persons with albinism reacted to sanitisers especially those at entry points in different facilities such as banks or shops. Some shop attendants refused to allow them to use their own sanitisers, and this led to a lack of access to many public facilities for persons with albinism."**[18]

The quote above shows that persons with albinism are potentially struggling to access basic services needed for their livelihoods such as food and health services; persons with albinism risk their health to access public facilities. These are some of the dilemmas that persons with albinism have to ponder daily in this Covid-19 pandemic, and this affects their mental health.

Access to Skin Cancer-Related Services

Another major health challenge faced by persons with albinism in Zimbabwe in this Covid-19 pandemic is accessibility to skin cancer prevention and treatment services. The onset of the pandemic triggered a series of lockdowns in Zimbabwe. Unlike many African countries, lockdowns lasted much longer in Zimbabwe.[19] These lockdowns were a great obstacle to accessing skin cancer treatment services and sunscreen lotions needed by persons with albinism to protect themselves from the harmful effects of the sun.

Research shows that persons with albinism are greatly affected by ultraviolet light. Without sunscreen lotion to protect them from the sun, 'persons with albinism are likely to develop skin lesions that have both cosmetic and health complications, with a high risk of developing skin cancers'.[20] Research shows that sunscreen lotion is very expensive in Zimbabwe.[21,22] Key informants revealed that one 250ml bottle of sunscreen lotion costs USD12-USD25 depending on the brand of the lotion. Therefore, many persons with albinism cannot afford these sunscreen lotions. They depend on Civil Society Organisations (CSO) such as the Zimbabwe Albino Association, ALCOZ and Alive Albinism Initiative to provide these lotions. The government does not provide these products, and this increases their vulnerability to skin cancer.

The extended lockdowns led to the closure of CSOs that assist persons with albinism. The only place where they could access sunscreen lotion was in a few pharmacies that remained open. However, sunscreen lotion is very expensive in these pharmacies. The few persons with albinism that could afford to buy from these pharmacies also had to deal with government restrictions of movement. Therefore, persons with albinism went for long periods without accessing these vital sun protection creams.

Secondly, persons with albinism are failing to access skin cancer treatment facilities.[23] In Zimbabwe, there is only one functional radiotherapy centre based in Harare at Parirenyatwa Hospital. This radiotherapy centre services every cancer patient in the country.[24] In the wake of the Covid-19 pandemic, all other health services were not prioritised. Some treatment wards were converted to Covid-19 wards. Access to radiotherapy became even more difficult during Covid-19. This greatly affected many persons with albinism who are likely to die early if they do not receive early treatment for skin cancer.

The relationship between albinism and skin cancer has been widely researched by the scientific community.[25] Existing research shows that skin cancer is the number one killer of this group and that many persons with albinism do not live past the age of 40 because of skin cancer-related illnesses.[26] Before the Covid-19 pandemic, many persons with albinism in Zimbabwe were battling skin cancer. The series of lockdowns installed by the government at the onset of the pandemic restricted movement.[27,28] There is still a huge concern amongst NGOs of persons with albinism that many of their members with albinism may have lost their lives because they could not access skin cancer-related health services. According to key informants, there are no statistics on skin cancer-related deaths of persons with albinism since the pandemic started, but they are still receiving reports of some of their members who died of skin cancer during the Covid-19 lockdowns. Hence, the lack of access to skin cancer facilities and skin cancer prevention measures such as sunscreen lotion further exacerbated the threat to the life of persons with albinism as compared to other groups of people.

Conclusion

Based on the discussions provided above, there is no doubt that Covid-19 has amplified the health and socio-economic inequalities experienced by persons with albinism in Zimbabwe. Though the pandemic has affected everyone in Zimbabwe, persons with albinism were already residing at the far margins of society before the pandemic and their circumstances just got worse. The Covid-19 pandemic has brought about potential health hazards for persons with albinism and it has exposed the pervasive nature of the social determinants of health. The discussion above shows the intersection between health and socio-economic issues; persons with albinism find it difficult to access basic goods and services because of their unique health needs. Furthermore, their right to life and right to the highest attainable health standards have not been fully realised, as guaranteed by the Zimbabwean Constitution and other regional legal frameworks. Persons with albinism's access to sunscreen lotions and skin cancer treatment services were greatly affected and this increased the threat to their life because of their susceptibility to skin cancer. Also critical to the discussion above was the fact that there have been policy attempts to lessen the burden of Covid-19 on people with disabilities, however, the extent to which such policy initiatives have altered the health and socio-economic outcomes of persons with albinism is still unknown. Therefore, future research must pay attention to emerging intersections between health and socio-economic issues of persons with albinism during pandemics.

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A SCULPTURE STOLEN FROM HEAVEN

Rufaro Martin Chinyanga

‘Rumbi, Rumbi look at that white guy!’
‘Mmm No iwe Nyasha Musope uyo (He is an Albino)’
‘So why is he white if you say his parents are black?’
‘Why are his eyes running around?’
‘Why can’t he see properly?’
‘Tell me, tell me....’

These are the daily questions I hear in the background as I go about my day on the streets of Harare. Sometimes I just ignore them, sometimes I react with anger and aggression towards those who raise them. However, sometimes I respond with humour and an educative twist. The word ‘Musope’ stirs volumes of emotions within me!

My name is Rufaro Chinyanga, but I’m also known as Rufaz. My name means joy and it’s something I try to live by daily but sometimes I struggle.

I was born and bred in a coloured neighbourhood in Zimbabwe. Living in a coloured neighborhood gave me a sense of belonging, given that most of the people were light skinned. They seemed not to have a problem with my albinism. My peers at the community playground accepted me. The community was closed to outsiders as they sought to preserve a western way of life and thinking. So as a child I participated in the social life of the community with my peers. We went fishing, bike riding, and gaming and even played pranks on the older members of our community. I was notorious for climbing my neighbours' fruit trees without permission whenever the fruits ripened. It was not all heaven though as domestic violence and drug-related crimes were a daily ordeal. My father had chosen this community as ideal for me and my sister, as he regularly confesses now in his older years. Here we knew about sunscreen lotions and herbal skin care from the coloured nurse aids who worked in white hospices and old children's homes. I felt normal.

The contrast came when I began primary school. The name calling, the physical aggression, and hostility I faced shocked me. I was white at home and at school I suddenly became black, but not black enough to fit in. I was an undesirable thing.

Initially I retaliated through violence, but I never won. I went home bruised and my spirit was low. I yearned for death at school but at home I was alive. As Zimbabwe's economic situation worsened, my beloved friends and neighbours left for the diaspora, mainly Europe and South Africa as they had ancestry claims there. This left a void as black families moved in, and the community's structure changed. The black children did not understand albinism and behaved like the children at school.

I retreated to a culture and lifestyle of reading books and watching TV, just to avoid people. Poetry became my love and an excellent tool for me to express my feelings and thoughts. When I took to stage, I was another person. Besides all of this, I was very reserved outside the school environment. As I progressed to university, I was amazed at the discovery of other young students like myself with various disabilities at the University of Zimbabwe. At university we had a department for disabled persons where we would gather and use our own facilities. The university treated us like royalty. Thus, we began to regain our confidence. I made friends with a lot of persons with albinism who were older than me. They had radical mindsets.

Thulani was one guy who stood out for me. He was a law student and very vocal. He became a student representative president. He was a brilliant orator. The girls loved him. Thulani became my role model and a close friend. He saw me performing poetry and linked me to a lot of university functions and national events. This then gave me exposure. My confidence levels rose. I became a rebel. I could now sweet talk women like any other guy. How I looked didn't matter anymore. The university experience for me was a blessing not only in terms of academics, but in nurturing my social interactions. I learnt how to fight back discrimination intelligently, using music and poetry and engaging in intelligent debate based on facts and evidence.

And since I am a poet at heart, I will share my deeper experiences and those of my peers with albinism in poetry,

White yet black I am and I stand to be
A symbol of curses to my African people
A ghost, a pig, a white man without a farm
A product of harlotry that makes it all contradictory just
Pondering about it silently

But I'm just white yet black
Listen up your African minds even the Caucasians
It's just a genetic condition, skin white, hair yellow
A sculpture stolen from heaven

But as I walk the streets of Zimbabwe
Streets of dust and colour,
Lights and shade, gold and plastics
Echoes in the air, man chasing the dollar,
    children running from crime, girls getting pregnant
And small boys becoming fathers
I hear these voices from my fellow Shona tribesman
You ghost, you pig, you half cast, skinned chicken
So, I go to bed every night with my heart in my hands
    constantly asking my mother
Did you have an affair with a white man?
But she always looks at me with eyes full of love and states
My son you are just white yet black

But I'm persecuted like the Messiah
Ignored like blind Bartimaeus
Imprisoned psychologically
Murdered practically
Ridiculed theoretically
Now what does this all add up to mathematically

She looks at me and says my son, my son
You are just white yet black
Black as they think they are
Even if they murder you, even if the segregate you
Even if they hide you or deny you love

You are just white yet black
A symbol of God's glory, a radiation of paradise
It's so amusing that one day we might all be in shock
At the sight in heaven my son when we find out that
    even Jesus and the angels
Are just white yet black …

Rufaro Chinyanga *is from Zimbabwe. He is a political science and law graduate of the university of Zimbabwe. His work focuses on advocating for the human rights of persons with disabilities, in particular persons with albinism. Rufaro is also a poet and musician. He uses these gifts to lobby for the rights of persons with albinism by writing prose and poetry...and doing live performances. He is passionate about changing the narrative for persons with albinism in Africa as someone with the condition.*

AN INTERSECTIONAL FEMINIST APPROACH IN ADVANCING THE REPRODUCTIVE HEALTH RIGHTS OF WOMEN WITH ALBINISM IN SOUTHERN AFRICA

Chisomo Kaufulu

Abstract

For reproductive rights to be meaningful for women with albinism, they must include the right to exercise informed decision-making concerning reproduction free from undue influence by third parties, such as health workers and family members.[1] Reproductive choice must safeguard the values and identity interests of women with albinism that reach beyond culturally imposed stereotypes and misconceptions about albinism.[2]

However, although various governments have taken progressive steps to advance women's reproductive health rights, the reproductive health and needs of women with albinism have largely been overlooked or undermined.[3] Even though women with albinism have the same rights concerning their reproductive health as other women, they also have needs and concerns that are unique which (when neglected) results in further violations of their rights on the basis of their disability.[4] Women with albinism often experience stigma, negative assumptions or misconceptions about their condition, discrimination and inadequate information when accessing reproductive health services.[5] With health systems sometimes imposing their own 'well-meaning' interests upon women with albinism, it is necessary to examine how the distinctively private and individualistic nature of reproductive health rights of women with albinism is to remain protected. I, therefore, argue for the incorporation of an intersectional feminist approach within reproductive healthcare systems and policy frameworks so as to effectively advance the reproductive health rights of women with albinism. An intersectional feminist approach is an integrated framework that encompasses principles of feminism and intersectionality. For the purposes of this article, an intersectional feminist approach, therefore, encompasses two

fundamental aspects. Firstly, it views disability through a feminist perspective by displacing entrenched patriarchal misconstructions about women with albinism and embracing a holistic understanding of the interaction between gender and disability.[6] Secondly, it acknowledges that reproductive health rights violations are not similarly experienced across all women with albinism, thereby enabling an interrogation into the manner in which different forms of social determinants intertwine and culminate into overlapping and entrenched barriers to services.[7]

How an Intersectional Feminist Approach can Advance the Reproductive Health Rights of Women with Albinism

The Approach Displaces Harmful Socio-cultural Narratives Relating to the Bodies of Women with Albinism

Women with albinism across the African region face stigma, prejudice, discrimination and hostility when accessing reproductive health services.[8] Due to their physical appearance, women with albinism are further perceived as being asexual and 'abnormal'.[9] Utilising a feminist approach unveils that such perceptions are deeply rooted within social-cultural norms that dictate women's bodily appearance.[10] The bodies of women with albinism are shrouded with myths and stereotypes in relation to their sexuality and fertility which have subtly found their grounding within healthcare systems. For example, whilst there may be a well-meaning intention in the provision of genetic counselling and testing to women with albinism, provision of such services may be subtly premised upon stereotypes aimed at eliminating the autonomy of women with albinism to exercise their reproductive choices free from undue coercion.[11] There are reported instances in which women with albinism are persuaded into not having children of their own for fear that their children will also be born with albinism.[12] Since society has prescribed what is deemed to be normal bodily appearance, the presumptuous response is to restrict the reproduction of women with albinism so that they do not pass along this 'abnormality' to their children. This is premised upon a harsh patriarchal misconception that the disability of a child is a hereditary defect arising solely from a mother's inherent bodily failures.[13]

There is therefore a need to review reproductive health service delivery and policy frameworks through a feminist lens in order to carefully interrogate dynamics around medical interventions and ensure that such interventions are not subtly influenced by stereotypical social norms and beliefs about the bodies of women with albinism. Albinism is not a natural state of inferiority or insufficiency and does not justify any negation of the autonomy of women with albinism in exercising reproductive choice. Reproductive health services and policies must always aim to ensure that women with albinism are recognised and respected as autonomous beings. Thus, they must be accorded the right to decide whether to bear children even in instances in which the children will likely have albinism as well.

The Approach Dispels Stereotypical Beliefs about Albinism and Motherhood

Prevalent stereotypical beliefs in society exist that undermine the ability of women with albinism in being capable mothers due to their disability.[14] In addition, women with albinism often live in poverty as they are subjected to inequitable access to socio-economic opportunities as a result of stigma, seclusion and discrimination.[15] Due to their socio-economic vulnerability, perceptions exist that the burden of childcare obligations (should they bear children) will then be transferred to extended family members who will have to bear the responsibility of looking after the woman with albinism and her child, or that both will become dependent on an already overburdened government welfare system. Such sentiments are usually premised on generalised beliefs that do not take into consideration a thorough assessment of the specific circumstances of a woman with albinism. Based on principles of intersectionality, women with albinism are not a homogenous group. They are not all equally disadvantaged, and they do not all possess equal access to resources, power and privilege. But even if the State or families may be providers of support for women with albinism and their children, it does not negate the fact that reproductive rights and entitlements remain applicable to women with albinism. Ironically, women without disabilities rarely undergo that same level of scrutiny to examine their 'capabilities' as mothers. Mothers without disabilities can rely on the care of others (nannies, family members and state welfare services, among others) in varying degrees in relation to child-care responsibilities without experiencing the same level of judgment as to whether that negates their ability to be mothers.[16] It must be accepted that interdependency in varying degrees remains the fabric of society.

Reproductive health services and policies must always uphold the bodily autonomy of women with albinism whilst ensuring an enabling environment to reasonably accommodate any need for support and assistance in their pursuit of motherhood. In the same manner that health workers inquire from other women without disabilities in relation to their reproductive plans,[17] the same should be afforded to women with albinism so that there is better management of unwanted pregnancies as well as supportive care for those seeking motherhood. In terms of the latter, health workers must have respectful open conversations with women with albinism in relation to any anticipated challenges that they are likely to encounter during pregnancy or child-care, and any options available for addressing or minimising such challenges.

The Approach Advances Evidence-based Services and Policies Informed by Women with Albinism

A feminist approach to albinism entails that we should retrieve and elevate the voices and experiences of women with albinism that are often misrepresented, silenced, or unheard. However, limited empirical evidence exists on the reproductive health needs of women with albinism. Hence, services and policies risk advancing interventions based on assumed needs not backed by empirical evidence. Women with albinism should not merely be data for policy makers but they must be meaningfully engaged in the construction of reproductive health interventions/reforms to better serve their needs. This is also where the capturing of intersectional experiences becomes key. An intersectional approach to albinism requires that the voice of those most affected by intersectional oppression are at the centre of interventions targeting them and in causes that are important to them. It is generally acknowledged that women with albinism face multiple and intersectional forms of discrimination.[18] Thus, there is a danger in rolling out an ineffective one-size-fits-all approach in reproductive health policies and service delivery if there is no recognition of the varied experiences faced by women with albinism. By utilising an intersectional approach in reproductive health service delivery and policies, policy makers can know (for example) how best to strengthen the accessibility of reproductive health services to women with albinism who fall within diverse social categories based on age, location, socio-economic status, educational attainment and ethnicity, amongst others. Policy makers and health service providers ought to be aware of intersectional experiences faced by women with albinism that results in compounded barriers or limitations in accessing/enjoying reproductive health rights. This will enable them to frame interventions that better serve women with albinism in cognisance of any multiple social identities that may exist.

The Approach Addresses Power Imbalances

Power imbalances exist in the reproductive healthcare system which enable abuse, neglect, and discrimination of women with albinism. Women with albinism usually become what is termed ‘captives of care’ under reproductive healthcare systems where they are prone to undue control, disempowerment and unnecessary intrusive procedures as well as forms of violence through abuse and neglect.[19] As earlier indicated, women with albinism constitute one of the most marginalised persons in many Southern African communities, with limited access to socio-economic opportunities. Their vulnerability, therefore, places them in a position in which they are perceived merely as docile subjects under the primary influence of healthcare professionals and policymakers over matters that could permanently affect their lives.[20] An intersectional feminist approach, therefore, entails examining power relations and eliminating the various ranges of unjust power relations that adversely affect women with albinism. It is therefore incumbent upon health systems to create an enabling environment that addresses power imbalances faced by women with albinism. Creating an enabling environment includes the removal of all physical and attitudinal barriers that directly or indirectly create power imbalances. This includes ensuring affordability (preferably free) of reproductive health services, setting up proper waiting shelters away from direct sunlight, provision of timely services to enable women with albinism to return promptly during the daytime so as to minimise the risk of attacks, availability of private consultation spaces, creation of safe and accessible feedback channels for complaints and provision of comprehensive regular training of all personnel (include front office staff) to dispel negative beliefs/attitudes against persons with albinism. In sum, levelling the playing field goes beyond simply recognising the rights of women with albinism but demands the creation of an enabling environment through provision of appropriate structures and resources for women with albinism to ably discharge their rights and exert control over their reproductive desires.

Conclusion

All in all, reproductive healthcare systems and policies need to incorporate intersectional feminist approaches to better advance the reproductive health needs and autonomy of women with albinism. In sum, this means that reproductive health policies and services must be wary of treating the reproductive health needs of women with albinism on a ‘group basis’ as opposed to individualised needs. There must be strategic efforts to ensure deliberate and explicit recognition of the varied circumstances of women with albinism and how such circumstances affect their reproductive experiences. In addition, women with albinism seeking reproductive health services should be viewed and treated as autonomous human beings and not merely as medical conditions. This includes being meaningfully engaged in the framing of reproductive interventions/policies.

Whilst motherhood is considered as a critical and fulfilling aspect for a considerable number of women, and having albinism does not negate that desire; this is not to generalise that all women with albinism wish to be mothers. What this paper advances is the provision of an enabling environment for women with albinism to exercise free and informed choice regarding their own reproductive desires.

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EDUCATION NOW: THE ROLE OF FAMILIES IN THE EDUCATION OF LEARNERS WITH ALBINISM IN ZAMBIA

Thomas Mtonga, Esther Lungu, Kalisto Kalimaposo and Joseph Mandyata

Introduction

Education plays a transformative role in human development, yet persons with albinism have been left behind in accessing education. In some cases, even those who access it drop out. This was confirmed by the Central Statistical Office[1] which found that out of the 15 000 persons with albinism of school-going age, only 37.3 per cent were at school, 37.5 per cent had dropped out and 25 per cent had never attended school.

Of all the stakeholders that ought to play a role in the education of learners, the immediate family plays a pivotal role in deciding to take the child to school, nurturing and supporting their education, encouraging the child to keep learning as well as providing protection and security. However, Mtonga et al,[2] identified the immediate family as one of the major deterrents and hinderances in the acquisition of education by children with albinism. It is against this background that the study sought to discuss and analyse the role played by the immediate family in the education of persons with albinism. The objective of the study was to establish the available support to obtain education for children with albinism from parents and families in the study sites and explore factors enhancing or hindering this support.

Methodology

The study, being qualitative in nature, used a phenomenological approach in the form of an interpretative research design.[3] Phenomenology can be defined as the exploration and description of phenomena, where phenomena refer to things, concepts or experiences as human beings experience them. The sample comprised 31 participants involving 19 learners with albinism (LWA), four parents, four teachers and four head teachers of schools where LWA were found. Data was collected using interview guides and focus group discussions (FGD), while purposive sampling procedure was used to draw the sample. This approach entails that specific participants were targeted as opposed to a random selection. Interviews were recorded using a voice recorder with permission from participants and the data obtained was analysed thematically. We obtained ethical clearance for the study from the University of Zambia, Humanities and Social Sciences, Research Ethics Committee.

Results and Discussion

Support to Learners with Albinism (LWA) from Parents and Families

The table below illustrates the experiences of LWA. It shows the extent to which these learners are supported by their families to obtain an education and the impact this has on their educational outcomes. The table compares sources of sponsorship for LWA versus their siblings.

RESPONDENT	STATUS OF PARENTS	SOURCE OF SPONSORSHIP	SPONSORSHIP OF OTHER SIBLINGS	PERFORMANCE AT SCHOOL	COMMENTS
LWA1*	Single parent	Missionaries	Father	Above average	Mother passed away. LWA being cared by Roman Catholic Church.
LWA2*	Single parent	Father	Father	Above average	The mother left the matrimonial house arguing that the birth of a CWA was caused by the family of the husband.
LWA3*	Married	Stepfather	Stepfather	Above average	Stays with mother and stepfather.
LWA4*	Married	Relatives	Parents	Above average	Cared for by grandmother.
LWA5*	Single parent	Irish Roman Catholic Sisters	Father	Poor	Has since dropped out of school and stays with grandmother.
LWA6*	Married	Social welfare	Parents	Average	Lives with both parents.
LWA7*	Married	Parents	Parents	Average	Lives independently now.
LWA8*	Single parent	Missionaries	Father	Above average	Lives with single mother.
FGD1*	Single parent	Liliane Fonds	Father	Below average	Stays with aunt: younger sister to mother. Mother passed away.
FGD2*	Single Parent	Don Bosco Fathers	Mother	Average	Stays with single mother.
FGD3*	Married	Parents	Parents	Below average	Parents are financially doing well but do not pay school fees and buy glossaries for their children with albinism.
FGD4*	Single Parent	Father	Father	Above average	Most of the times, the father does not pay fees for the LWA.
FGD5*	Single Parent	Parents	Mother	Average	Stays with single mother. Father supports him.
FGD6*	Married	St. Paul's Roman Catholic Missionaries.	Parents	Average	Parents live together.
FGD7*	Single Parent	Social welfare	Mother	Average	Stays with the single mother.
FGD8*	Single Parent	Parents	Parents	Above average	Lives with a single mother.
IWL1*	Single Parent	Missionaries	Father	Above average	Stays with father and step mother.
IWL2*	Single Parent	Father	Parents	Above average	Stays with father.
IWL3*	Married	Relatives	Relatives	Average	Both parents are dead.

*LWA: Learner with albinism; FGD: Focus Group Dicussion; IWL: Learner with albinism not in school

Photo Credit: The Conversation.
Children with Albinism in the Classroom.
Retrieved at theconversation.com

The previous table shows that 12 out of 19 parents to LWA were single parents. Most of them divorced at the birth of a child with albinism. Eight out of 19 families supported their own LWA*. Fathers of LWA who were separated from their mothers in the majority of cases were sponsoring the education of the other children in the family but not their own child with albinism. This trend was repeated even where the parents of LWA were together. The table also shows that only 47.3 per cent of LWA performed above average, a possible indicator that the absence of support for their education had a negative bearing on their performance.

*LWA: Learner with albinism

Factors Influencing Family Support for LWA in Education

Myths and Beliefs

There are a number of myths and beliefs within society that have a bearing on the support immediate family members of children with albinism (CWA) provide for their education. Some of these myths which have been well documented include the erroneous belief that the body organs of persons with albinism such as hair, nails, and genitals, have powers when used for ritual purposes to bring good fortune and healing. Another myth is that persons with albinism do not grow old but simply disappear before they reach middle age. This is based on the belief that they are not true human beings. They are ghosts. Particularly damaging to children with albinism are beliefs that they are dull and are intellectually disabled, and that their birth is a result of a curse.

These myths, superstitions and beliefs influence how immediate families treat LWA including the support they provide for their education. One parent (PT2) observed: 'We are always afraid of sending our children with albinism to school because of these attacks on LWA'. Another mother whose nine-year-old boy had his hand chopped off stated: 'My son was dying at the hands of those brutal murderers. It is better he dies at my home instead of being killed when he goes to school. I will keep him at home'.

Speaking of how his father does not consistently pay his fees, leading to him being unable to attend school for long intervals, FGD4* stated:

> **"Daddy is the one who pays for my school fees but he does not pay as required just like MM has stated. I don't know, even last year I did not come to school for the whole year. He told me that I should wait until he pays for my other brothers and sisters …. The reason why my father does not want me to come to school is because he wants my hair so that his business does well."**

Adding to the discussion, TR4*, presented that:

> **"Here at school, we have also observed that there is minimal support towards learners with albinism from their parents or relatives. Like the boy we have been talking about, the relatives are doing quite well in life. But we were surprised that the whole of last year and part of term one, the boy was not brought to school. Then, we learnt that his relatives were wondering whether he would finish school because of the myths that people with albinism do not grow old instead they disappear in their youth."**

*FGD: Focus Group Discussion; TR: Teacher

Similarly, LWA4* narrated that:

> **“I did not go to school in Grade 10 first term, because my parents could not find money for me. Yet, the relatives to mum are doing very well financially. Until my grandmother called them all and told them about my plight. So, some of them were very open and said that we do not want to get involved in the education of this child because you know his condition?”**

A Head Teacher interviewed (HT3*) reported:

> **“You know sir, because of the myths and beliefs about LWA, the parents of LWA will not be ready to pay for their children’s school fees. But for the partially and totally blind children you will find that parents will fight by all means to ensure that their children go to school even if they are poor.”**

*LWA: Learner with albinism; HT: Head Teacher

From the quotations presented above, it is evident that myths and beliefs about persons with albinism have an effect on what decisions parents make towards the education of LWA*. For instance, some parents are reluctant to send their LWA to school for fear of having their children killed. Parents also decide not to send their children to school because of the belief that the hair of a person with albinism can help boost business or help fishermen catch more fish. Owing to this belief, these parents do not send their children with albinism to school with the hope of making money from the selling of their hair, nails and bath water. Similarly, those who believe that LWA are dull or intellectually disabled and that they die at an earlier age would not want to sponsor their children's school fees, thinking that they would waste their money. Besides all these issues, the observations made by administrators that parents of LWA would rather support the education of children without albinism than paying for their LWA confirms the assertion that parents are reluctant to support the education of LWA.

Breakdown of Family Structure

The birth of a child with albinism is traumatic and in contexts where albinism is not well understood quite often leads to parents of the child divorcing or separating due to myths and beliefs surrounding albinism. In relation to the findings above 68 per cent of LWA came from families in which the biological parents were no longer together. Thus, many children with albinism are being raised without the support of both their parents, creating financial difficulties and an inability to afford education. Most LWA categorically stated that they had challenges with schooling because their parents were separated. LW8 stated that: "I know sir that I have had financial challenges in school because of the divorce of my parents. I am told that my father is doing well financially but he does not even want to hear anything about me. So, there is no one to motivate me or encourage me to work hard at school." Similarly, LWA5 also stated:

"I stopped school in my grade seven because the Irish sisters who were supporting me left Zambia and went back to their country. My parents divorced when I was young and I was taken to school by my grandmother whom I stay with. But she could not raise money for me to buy books and uniforms."

Eighty-four per cent of the LWA were not sponsored by fathers. In contexts like this, where fathers tend to be the bread winners in families, their absence and withdrawal of support has dire consequences for the education of children with albinism.[4]

*LWA: Learner with albinism

Abuse by Family Members and Friends

The study also revealed incidences of abuse of children with albinism at the hands of extended family members and friends. For instance, Head Teacher (HT3*) said:

> **“You know, whatever happens to these LWA*, at least a member of the family must be involved. We had a girl with albinism here at school. When the issues of attacks on persons with albinism became common, they came and withdrew their child from school. To date, we do not know where that girl is. It is not known whether they withdrew her for fear or they had other intentions. We have tried as a school to find out from friends who were coming from the same place where she used to stay. We hope she has not been killed or sold off to witchdoctors for charms.”**

Similarly, a Community Radio Station reported that a nine-year-old boy of Mthwalo Village had his hand chopped off by the friends of the boy’s uncle. It is alleged that a lot of attacks on persons with albinism were orchestrated by friends or relatives within the community. Additionally, a mother of a school going girl said:

> **“Every time my girls went to school, I used to be so afraid that maybe someone would attack my daughters. Sir, you know that most of the people who attack our children are our own relatives and friends. They are the ones who know where we stay, our movements and our activities.”**

A Zambian tabloid,[5] reported an incident where an uncle of a grade six boy with albinism in Lusaka asked permission from the child’s mother to take him shopping so he could buy school shoes for him. It was later discovered that the uncle was using this as a pretence to abduct the boy and sell him. After this discovery, it is reported that the boy did not want to go to school for fear of encountering his uncle and the mother was afraid for the life of her son.

The abuse also extends to sexual assault. Head Teacher (HT1) said:

> **“I discovered that a girl with albinism at my school was pregnant. After she gave birth, I made arrangements for her to learn at a nearby school. Three months later, I was told that the girl was suffering from high blood pressure. I went to pick her and took her to some close friends where the girl disclosed how she was sexually molested at home by extended family members and friends of the family.”**

*HT: Head Teacher; LWA: Learner with albinism

Harmful Practices

The study also discovered that some LWA*, as a result of myths around albinism, were being subjected to harmful practices by family members which negatively impacted on their access to education. For instance, some girls with albinism are not allowed by their families to go to school because the families benefit from harvesting these girls' hair and nails for profit. Head Teacher (HT1*) who has seen these practices narrated:

> **"Some girls with albinism are really abused. In one case, a girl was being used by her parents to supply hair, nails and bathing water for [to] sell to fishermen. The parents used to make money with the same girl. When she came to school, it's like they lost the source of income. So, later on, I noticed that the girl did not come to school, and I decided to follow up."**

A teacher explained that they had lost a number of girls with albinism at the school to men who enticed them with marriage proposals but had insidious intentions. Teacher (TR4*) explained that:

"You know, it would be during the sexual act that these businessmen would pluck some pubic hair from these girls with albinism, and they would sell them as charms for fisherman to catch more fish.' Perhaps this partly explains why the Central Statistical Office found that more women and girls with albinism were married compared to men."

Though more prevalent amongst girls these harmful practices also affect boys. For instance, FGD4* mentioned that his father would sell his hair as charms to business people.

Conclusion

From the study above, it is evident that family members of LWA play a role in their children's education. However, myths and beliefs held about persons with albinism and the consequent harmful practices against them, the weakening in family structure impact negatively on the education access and outcomes of LWA. There is a need for greater support and sensitisation of families of children with albinism.

Recommendations

- Government should intensify efforts to provide public education on albinism, particularly addressing erroneous myths and beliefs about the condition.
- Families of children with albinism must be provided with targeted and appropriate training on albinism and the rights of children with albinism including their right to education.
- The government must build capacity of educators as well as for all other relevant sectors to enhance the promotion and protection of the right to education of children with albinism.
- Where needed, children with albinism should be registered with the Ministry of Social Welfare and Community Development to benefit from the country's social protection system.

*LWA: Learner with albinism; HT: Head Teacher; TR: Teacher; FGD: Focus Group Discussion

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TO ALL PERSONS WITH ALBINISM, FROM A GIRL FROM TSOLOANE, LESOTHO

Masekara Sekoankoetla

My name is Masekara Sekoankoetla. I was born and raised in Tsoloane, Mohale's Hoek, in the Southern part of Lesotho. I am the fifth child and the second one with albinism in my family, after my eldest sister. I am a village girl.

This is my story.

When I was around three-years-old, I was supposed to begin pre-school. Excited and expecting like any other child to go to a nearby school with my peers, my bubble would be burst by my mother who told me that I could not go to school yet. She said that I would learn things that are taught at school at home. Mother explained that it was not safe for me to go to school that young as I would be bullied and ill-treated like my eldest sister. Well, I thought it wouldn't be that hard as I was always by her side. We even went to the veld to herd sheep together. At our leisure time, when the sheep were grazing, mother would teach me how to read and write. It was so much fun. During that time, I was not allowed to visit or play with many children in the village as my mother was fearful for my wellbeing.

I faced my toughest times when I went to Grade 1. The other children looked at me like I was an alien. They called me a myriad of derogative and humiliating native names and refused to play with me. Some of the students would not touch things that I had touched out of fear that my albinism was contagious. Others discouraged the few who interacted with me saying that they will have kids with albinism in future. This ordeal was unbearable. I preferred being around my mother for lessons, and in the company of my siblings and my dad. I remember the day when the lunch provision for some kids was stolen (apparently eaten) but my bread had been mixed with sand. Some students laughed saying 'No one could eat her bread'. I told my parents and older siblings that I no longer wanted to go to school but they insisted I must. My brother would always fight for me and gained the name 'Arcola', which insinuates that he is as cheeky as the farm worker.

It took my mother's bravery for me to remain in school. She went to the principal and explained my situation and the accommodations and support that the teachers had to avail for me to participate meaningfully in both the academic and extra-mural activities. She also encouraged me to stand in front of the chalkboard anyway, despite the quarrels from other students that I obscured their vision. I then realised that I am responsible for my happiness and freedom. Over time I further realised that the more I refused to succumb to mockery and intimidation, the more my abusers and bullies gave in. This realisation and the fact that my parents and five siblings were very loving, and comforting gave me confidence.

When I started secondary school, I met similar challenges as in primary school. Thank God, this time I was more confident and assertive. I explained to the teachers beforehand my needs and the accommodations that I needed. Life became easier because of the support I got from them. I was not ashamed to sit alone at the front when we were doing the classwork. I remember when I was in Grade 8, students were not allowed to wear anything on their heads. I advocated for the wearing of both the summer hats and woollen hats in winter as I explained that it will not only benefit myself but others with eye problems.

My assertiveness did not only open the door to my social acceptance but also raised my political status as I was elected head prefect for two consecutive years at secondary school. It was during this time that I realised my potential in advocacy work, and I started to dream of becoming an advocate. Although my social exclusion at a very tender age was an unbearable plight to me, it has also built me. I advocated for myself through my life as a student believing that I also deserved a better place in society which I always believed against all odds.

I really thank my mother and my family for their support for me to stand tall until I could stand on my own. I am now a human rights lawyer and activist. I advocate for social justice with specific focus on minority groups including persons with albinism. I have opened a Facebook page titled 'Albinism appreciation – Bosofe', where we discuss issues surrounding albinism and advise, empower and support persons with albinism and their families.

I also look forward to advocating for persons with albinism to benefit from the social grants and assistance in kind offered by the government of Lesotho under the Ministry of Social Development. Sunscreen is a basic need for persons with albinism and I believe that those who cannot afford it need support, primarily from the government.

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THE ROLE OF NATIONAL ACTION PLANS IN ADVANCING THE ECONOMIC, SOCIAL AND CULTURAL RIGHTS OF PERSONS WITH ALBINISM IN SOUTHERN AFRICA

Sethu Mbuli-Robertson

Introduction

Since 2006, over 700 attacks and other grave human rights violations against persons with albinism have been reported across 29 countries in the Africa region.[1] These attacks are a result of a broader issue of discrimination, primarily based on an intersection of disability and colour. In particular, women and children bear the brunt of the global discrimination faced by persons with albinism.[2]

In an effort to combat these violations, the former United Nations Independent Expert on the Enjoyment of Human Rights by Persons with Albinism, Ms Ikponwosa Ero, brought stakeholders together to elaborate on and adopt a Regional Action Plan on Ending Attacks and Human Rights Violations Against Persons with Albinism in Africa (RAP) (2017 – 2021).[3]

The RAP consisted of 15 measures spread across four pillars of Protection, Prevention, Accountability and Equality and Non-Discrimination. In 2018, 40 targets were adopted to realise the measures identified in the RAP. Those targets were also linked to the AU's Agenda 2063 and the UN's Agenda 2030: the Sustainable Development Goals (SDGs) and the central pledge to leave no one behind. These linkages were to facilitate and mainstream implementation by Member States and other key stakeholders.

In 2019, the RAP was considered and adopted by the African Union meeting of Ministers of Social Development, Labour and Employment. It was subsequently adopted with its implementation matrix, in the same year, by the African Union Executive Council as a Plan of Action (PoA). The official title of the PoA is the Plan of Action to End Attacks and other Human Rights Violations Targeting Persons with Albinism (PoA, 2021 – 2031).[4]

The PoA identifies the strategic outcomes, priority actions, responsible entities, indicators and data collection mechanisms necessary to achieve the measures of the PoA. Using a results-based management approach, the PoA also encourages the participation and collaboration of stakeholders to ensure the effective implementation of the plan at the national level through National Action Plans (NAPs) on albinism. It highlights the importance of states adopting National Action Plans in ensuring the PoA's Strategic Outcomes are met.

By highlighting relevant and related provisions, the Plan plays a vital role in the progressive realisation of the economic, social and cultural rights of persons with albinism. For instance, Priority Action 1.1(c) read in conjunction with Strategic Outcome 4.3 on access to adequate healthcare emphasises the importance of states building the capacity and knowledge of healthcare workers in order to protect the right to health of persons with albinism. The Plan also highlights that to ensure adequate healthcare reaches persons with albinism, those that live in rural areas must be included. Particular emphasis on skin cancer prevention treatment, low vision support and dermatological care is made, which are many of the concerns and barriers persons with albinism face in Africa.[5]

Equally, Strategic Outcome 1.3 on enhancing access to education and skills development, together with Outcome 4.2 on access to inclusive education, steers African countries towards realising the right to education of students with albinism. The Plan emphasises the importance of training teachers on albinism and integrating albinism within existing curricula to foster a non-discriminatory environment for children with albinism. Strategic Outcome 1.4 on technology places emphasis on the availability of affordable and context-based assistive technologies as essential components for persons with albinism to access education.

Stressing the importance of strengthening social protection for persons with albinism in vulnerable situations, including the implementation of inclusive social safety-net mechanisms and the integration of persons with albinism within pro-disability mechanisms, Strategic Outcome 2.3 further supports the right to an adequate standard of living for persons with albinism.

Overall, the PoA mainly addresses these rights under the Equality and Non-Discrimination pillar, with priority actions reiterated across Strategic Outcomes where there are similarities to show an interconnectedness approach to addressing concerns. A key priority action identified in the Equality and Non-Discrimination pillar is the need for states to enact laws prohibiting discrimination based on colour. This is important because while the PoA is incorporated in the larger disability architecture of the African Union, many disability frameworks only give persons with albinism protections based on their visual impairment alone. However, research indicates that persons with albinism also encounter discrimination based on their appearance and colour; therefore, a more intersectional approach is needed.

The AAN, its Mission and Processes to Assist in NAP Development

Currently in its pilot phase (March 2021 – March 2023) the Africa Albinism Network (AAN) is a consortium of non-governmental organisations working to promote the dignity and welfare of persons with albinism in Africa through policy development and implementation. The Network's core mission is to promote the adoption and implementation of the PoA through the development of National Action Plans.

With support and guidance from the AAN, eight countries are developing NAPs in line with the AU Plan of Action. These are Kenya, South Africa, Malawi, Tanzania, Mozambique, Uganda, Togo and Zambia. To date, only three of these have adopted NAPs, two of which have multi-year budgets. It must be noted that a number of these countries were already working on a NAP on albinism based on the Regional Action Plan or solely through national advocacy even before the AU Plan of Action was adopted. This includes Kenya and Mozambique who in 2010 and 2015 respectively adopted their NAPs. Zambia is the only country the AAN is working with which, despite recorded attacks, had not begun to develop a policy framework to end attacks and other violations experienced by persons with albinism in the country.

The team works with countries that have reported attacks against persons with albinism and are close to or have already adopted NAPs. The AAN also chose to work with these countries in order to learn from their past experiences and to assist them in moving forward.

The AAN uses a seven-step process for NAP adoption that was developed from the experiences of countries that have gone through the process. The seven-step process is also informed by the experience of AAN's lead technical advisor and former UN Independent Expert on albinism, Ms. Ikponwosa Ero. It involves engaging a wide range of stakeholders across multiple sectors and holds much potential to expedite the adoption of NAPs at country level, strengthening the realisation of socio-economic rights for persons with albinism in Africa.

The first two steps include meeting with non-governmental organisation representatives from the country in question and identifying a national partner to drive the NAP process.

The AAN team, in coordination with the national partner, will then facilitate a meeting of representatives of national groups to nominate –

in consideration of ability, geography, and gender among other criteria – a National Albinism Task Force to lead the NAP process (third step). In addition to national albinism groups, the National Task Force includes other pertinent stakeholders such as government representatives and representatives from National Human Rights Institutions, among others.

The last four steps of the AAN process involve supporting the development and review of a draft a NAP by the Task Force, promote its adoption by the state, and its implementation thereafter. The AAN shares their process with stakeholders interested in developing their own NAP and provides guidance from lessons learnt in the process.

Below is a discussion providing insight to where the countries AAN work with are in the process of developing, adopting and implementing NAPs and the ways in which these countries have incorporated economic, social and cultural rights and how the Network has assisted in strengthening these provisions.

National Action Plan Overview

South Africa

In August 2021, the South African albinism sector submitted to their government the 'National Action Plan on Persons with Albinism in South Africa: An Integrated Plan to Protect, Promote and Uphold the Rights of Persons with Albinism in South Africa'. The Plan is currently being considered by the government and has not yet been adopted. Meanwhile, persons with albinism in the country faced exacerbated discrimination in the wake of the Covid-19 pandemic.

Many were denied pandemic support, in the form of food parcels given to persons with disabilities, with authorities asserting that persons with albinism do not qualify. Organisations also saw an increase in gender-based violence cases involving women and children with albinism. Furthermore, many persons with albinism could not travel to hospitals to get sunscreen due to hospitals closing nonessential operations.[6]

These concerns which existed before the pandemic, were amplified during the pandemic. Persons with albinism are disproportionately impacted by the high unemployment rate in the country, as many of them do not complete their education due to a lack of reasonable accommodation in schools, they struggle to get employment in the open labour market.[7] Those who are qualified do not always get employment commensurate with their qualifications due to discrimination.

The South African NAP addresses the above concerns and others relating to economic, social rights of persons with albinism. The relevant sections include the following pillars: access to adequate healthcare services, access to inclusive education and training, employment and an adequate standard of living and the pillar on reducing econometric vulnerability and releasing human capital.

While the initial drafts of the NAP had a strong focus on addressing economic, social and cultural rights and enhancing access to these rights for persons with albinism, a key recommendation from AAN was for South Africa's NAP to integrate the recommendations that South Africa had already gotten from human rights bodies including the Committee on the Rights of Persons with Disabilities (CRPD) and the UN independent expert following her country visit to the country on these issues.[8] The AAN also suggested that in framing these issues the local context or lived realities of persons with albinism in the country are taken into account.

The subsequent drafts of South Africa's NAP reflect these suggestions.

The NAP as a result emphasises the importance of access to quality sunscreen in all provinces of the country, especially in rural areas; the need to include cancer as a priority in the National Cancer Strategy; the provision of learner transport for children with albinism who have to travel long distances to get to school and the development of programmes that support the achievement of full and productive employment, decent work and equal pay for work of equal value for persons with albinism in the country.

Uganda

In Uganda, persons with albinism also face many challenges, including erroneous beliefs that lead to their discrimination, impacting their ability to access essential social services. Persons with albinism were not included as persons with disabilities in the country's Persons with Disabilities Act of 2006. This resulted in disaggregated data concerning persons with albinism not being collected during the national population statistics on persons with disabilities.[9] Although the Persons with Disability Act 2019 later included persons with albinism, much still needs to be done to ensure the equal enjoyment of rights by this group.[10]

The Uganda National Action Plan for Persons with Albinism 2020-2025 has been drafted and was adopted by the government on 13 June 2022 amid celebrations of International Albinism Awareness Day.[11] The NAP covers economic, social rights issues across several priority areas of the plan, mainly under access to adequate healthcare, access to all levels of education, and access to work and employment. In its review, the AAN recognised the influence of both the RAP and the 2018 research report 'Enhancing Equality and Countering Discrimination against Persons with Albinism' on Uganda's NAP on the Plan.[12]

The Network suggested additional measures and objectives that could be added to the NAP to enhance the realisation of socio-economic rights of persons with albinism. Under the pillar on access to adequate healthcare services, for instance, the AAN suggested that the NAP could recognize the importance of informal health systems and practitioners, including traditional midwives, in providing care for persons with albinism and the need for these actors to be provided with relevant training on albinism. Additionally, due to geographic disparities, access to healthcare services for persons with albinism based in rural areas needs to be emphasised.

Under the pillar on access to all levels of education, AAN suggested emphasising access to inclusive, equitable and quality education to guard against children with albinism being sent to separate or 'special' schools. Moreover, it was suggested the NAP mentions the importance of the inclusion of albinism education in overall school curricula and adds an indicator on teachers training on albinism.

Tanzania

In Tanzania, the overall decline in reported attacks against persons with albinism and the pro-activeness of local authorities have been commendable. Still, the root causes of attacks against persons with albinism have yet to be properly addressed. Additionally, there are concerns around the high risk of skin cancer among persons with albinism.[13]

The country's National Action Plan for Persons with Albinism 2022 – 2026 expanded on these concerns and highlighted measures to be adopted to address them. In its review, the AAN commended the NAP for domesticating and contextualising the RAP to the local context, showcasing similarities between the country's NAP and the PoA. However, the document has yet to be adopted by government, three years following its submission.

The Plan mainly addresses economic, social and cultural rights under the protection and equality and non-discrimination pillars. The former expands on measures to ensure persons with albinism access healthcare services and facilities, including the rollout of cancer treatment strategies and access to sunscreen. Under the equality and non-discrimination pillar, the NAP notes strategic actions to improve the economic security of persons with albinism, including the provision of housing, the implementation of income-generating initiatives and the inclusion of persons with albinism in poverty alleviation programmes.

In further reviewing the Plan, particularly the pillar on protection, the AAN recommended emphasising the importance of training vision providers on specific ocular and visual aspects of albinism and how to effectively manage refractive correction and the magnification needs of persons with albinism, which was not included in the document.

Mozambique

The Republic of Mozambique adopted the Multi-Sectoral Action Plan to Address the Issue of the Protection of Persons with Albinism (2015-2021) in 2015. The document aimed to guarantee protection and social assistance for persons with albinism. This is evident in its focus on medical assistance and the provision of prescription eyeglasses to persons with albinism, and in providing social assistance to persons with albinism and their families.

As Mozambique prepares for and drafts the next NAP, the AAN has made several recommendations to strengthen the Plan, especially as it relates to advancing the economic rights of persons with albinism. The Plan highlights these rights most substantially under the 'guarantee protection and social assistance to persons with albinism' goal.

Here, the AAN recommends that the next Plan should strengthen the country's priority actions relating to access to decent work for persons with albinism, through either waged employment or self-employment and access to reasonable accommodation for persons with albinism in the employment sector as set out in the PoA.

Overall, Mozambique had a good National Action Plan, which along with Malawi's NAP, informed the creation of the Regional Action Plan. However, no budget has ever been allocated to the Mozambique NAP, despite extensive government involvement. In early 2022, the AAN in partnership with UNESCO hosted a two-day NAP review workshop in Mozambique, intending to strengthen the implementation of the Plan.

Malawi

The National Action Plan on Persons with Albinism in Malawi 2018 – 2022, as mentioned, was instrumental in the creation of the RAP. And although the government has adopted the NAP, concerns regarding its coordination, implementation and lack of a budget remain. However, AAN and the Malawi Human Rights Commission (MHRC) are working with the Association of Persons with Albinism in Malawi (APAM), among other stakeholders, to review and extend the NAP.

Enumerating seven strategic areas, the Plan includes a focus on fast-tracking access to justice, access to affordable healthcare services and offering public safety for persons with albinism, among others. In its report on the implementation of the NAP, the MHRC noted that security, access to sunscreen lotion and negative attitudes were still persistent concerns, despite the implementation of the first NAP.

Zambia, Togo, and Kenya

While some countries have documented success in drafting and adopting NAPs, others still face challenges. In Zambia for instance, the continued disagreements between different organisations representing persons with albinism have resulted in the stalling of the NAP drafting process.

In Togo, the Strategic Plan for The Socioeconomic Inclusion of Persons with Albinism in Togo 2018–2022 has been implemented at the civil society level without government adoption. Despite the challenges they have faced, their experience shows the impact civil society organisations can make where government support is delayed or absent.[14] AAN has plans to work with Togo, to review and inform the next stages of their NAP process.

And while Kenya does not have a written NAP, a budget was allocated to the albinism sector. This is not ideal, as accountability and transparency are a concern, and government may stop funding without notice. AAN is currently working with the country, which is currently in a consultation phase of the NAP.

NAP Adoption and Implementation Challenges

Despite the progress made by each country, there are still several challenges that hinder the successful adoption and implementation of NAPs, some of which have been shared above. Chiefly, albinism organisations, government and other stakeholders generally know very little about the AU Plan of Action and its implementation matrix. The AAN is working on raising awareness and engaging different partners about the relevance and importance of the PoA to issues of persons with albinism.

Furthermore, the NAP process requires albinism groups to work together for its successful adoption. This unity prerequisite is often difficult in the absence of an organised albinism movement or where there is no history of positive collaborative engagement among the existing groups of the national albinism movement. This is exacerbated by a lack of human and financial resources such as limited staff with strategic advocacy skills and limited professional experience as a whole.

Other challenges include the feasibility of some of the draft NAPs. Some of them, such as the NAP of Uganda, are extensively detailed and lengthy, raising the issue of whether it can easily or realistically be implemented within the given timelines.

Additionally, there's often a lack of proper monitoring and coordination of actions carried out under some NAPs. This was observed during the review of Malawi's first NAP. In Kenya, the lack of a written NAP results in little to no transparency in the use of allocated funds, a potential reason for government to withdraw support of the NAP in future. In Togo, the NAP was adopted at the civil society level. Without government buy-in or ownership of the NAP, the government will not allocate resources or funds limiting the impact of the NAP can have in the country.

Finally, there is the challenge of length of time taken by the government to adopt the draft NAPs. The albinism communities in South Africa, Tanzania and Uganda have been waiting for government to adopt the NAP for between two to four years now.

Some of the above challenges could be addressed by the appointment of the AU Special Envoy on Albinism, a position and office that can play an instrumental role in fostering the adoption of NAPs at the government level. Although the AU has committed to establishing the role, no funding has been set aside and no appointment has been made to date.

The Potential for NAP to Advance ESC rights in the Southern Africa Region

Despite the above challenges, the adoption of NAPs remains important for strategic interventions relating to socio-economic rights of persons with albinism. Additionally, the NAP development process helps the albinism community speak strategically through one agenda. These in turn encourage governments and other stakeholders to invest in persons with albinism.

And in spite of the current challenge of government adoption, it is still highly beneficial for the albinism community to draft NAPs with like-minded organisations, as seen in Togo. These could include National Human Rights Institutions, organisations of people with disabilities, development partners and other relevant civil society organisations. As NAPs domesticate the PoA on a national level, they remain an authoritative compendium of priorities of the albinism community for all relevant stakeholders, such as the government, funding organisations and development agencies.

It is hoped that the current and future National Action Plans being drafted will adopt a human rights-based approach with a particular focus on ensuring full recognition of the economic, social and cultural rights of persons with albinism in these countries.

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THE ROLE OF THE NATIONAL HUMAN RIGHTS INSTITUTION IN ENSURING PROTECTION OF THE RIGHTS OF PERSONS WITH ALBINISM IN MALAWI

Bonface Massah

Abstract

The Malawi Human Rights Commission (the Commission) is an independent national human rights institution established by the Constitution of the Republic of Malawi under section 129. The Human Rights Commission Act (HRC Act) fleshes out in more detail the organisation and operation of the Commission. The primary function of the Commission as set out in section 131 is to protect and investigate violations of the human rights accorded by the Constitution or any other law. The Commission working alongside the Courts and Ombudsman has the authority to investigate human rights violations, both on its own initiative and in response to a complaint, and provide redress for complaints of human rights violations made by an individual or group of individuals it receives.[1] The Commission's investigative power is far reaching. It can conduct investigations including in jails or police cells with or without notice, hear evidence from anyone, and gather evidence for assessments of human rights without any restrictions. According to the Commission's Strategic Plan 2018 – 2022, it has maintained its 'A' status accreditation as per the Paris Principles and adopted Resolution 74/156 by the United Nations General Assembly.

The ensuing discussion gives an overview of the role played by the Commission in promoting and protecting the economic, social, and cultural rights of persons with albinism in Malawi in accordance with its legal duties and authority. It describes complaints of alleged human rights abuses of persons with albinism that the Commission has received in recent years and how the Commission has dealt with these complaints.

Human Rights Violations against Persons with Albinism in Africa and Malawi

The Global Disability Report 2011 estimates that people with disabilities make up 15 per cent of the global population with 70 per cent of them residing in developing countries like Malawi.[2] According to Malawi's 2020 Census, the country has a total population of 17 563 749 people, 1 556 670 of whom have a disability. With a prevalence rate of 10.4 per cent; persons with albinism make up 0.8 per cent of the total population of persons with disabilities.[3]

A study conducted by Amnesty International in 2016 found that since 2014, Malawi has seen an upsurge in reports of human rights violations against persons with albinism, including kidnappings, grave robberies, and ritual killings.[4] These findings were echoed in a report on the country visit to Malawi by the United Nations Independent Expert on the Enjoyment of Human Rights by Persons with Albinism (IE on albinism) carried out the same year. According to the IE on albinism systematic human rights abuses in Malawi have caused persons with albinism to live in continual fear and trauma and in desperate need of help to regain their dignity.[5]

There have been 809 attacks and mutilations reported in 28 countries across Africa from 2008 to 2022, including murder, kidnapping, trafficking of body parts, and graveyard exhumations. The Regional Action Plan on Albinism in Africa (2017 – 2022) and its successor, the Plan of Action to End Attacks and Other Human Rights Violations Targeting Persons with Albinism (PoA, 2021 – 2031) note that harmful practices, allegations of witchcraft, and ritual killings against persons with albinism have resulted in significant violations of human rights, frequently resulting in victimisation through stigmatisation, death, grave degradation, and removal of body parts. The attacks on persons with albinism pose a serious threat to their right to life and constitute a serious violation of their human rights.

Two hundred and thirty two (232) persons with albinism have been killed in total across Africa, with 25 per cent of the attacks taking place in Malawi.[6] According to statistics provided by the Malawi police service, between 2013 and 2022, 195 cases of attacks against persons with albinism were reported in Malawi, with a regional distribution of 120 cases (62 per cent) in the country's southern region, 58 cases (30 per cent) in the central region, and 16 cases (8 per cent) in the northern region. The number of attacks peaked in 2016, when Malawi recorded 60 attacks.[7]

Research has shown that these crimes are fuelled by perilous myths and superstitious beliefs. The attacks against persons with albinism are normally part of organised crimes. Family members and close friends are oftentimes involved in the commission of these crimes, colluding with assailants for financial gain. The attacks in Malawi according to a report by Amnesty International in 2018, which tracked the pattern of attacks, occur frequently during the farming season and are a combination of many factors, such as poverty, corruption, the widely held belief in the use of magic in business.[8] Malawi's struggle to put effective measures in place to end attacks is evident in the resurgence of attacks that increase fear among the population.

The Commission's Interventions

Conducting Public Inquiry

In the wake of these reports, Malawi's Human Rights Commission conducted a public investigation in 2016 into the status and protection of persons with albinism in Malawi. The main objective of the investigation was to gather information on the human rights situation of persons with albinism that could be used in designing and implementing effective interventions to address systematic human rights abuses against the albinism community in Malawi.

The main findings of the public investigation were that many young people and adults with albinism in Malawi had experienced human rights violations including ritual killings, the harvesting of body parts, kidnappings, the exhumation of tombs. The investigation found that traditional beliefs, myths, and misconceptions contributed to the atrocities committed against the community in Malawi. The public inquiry discovered various inconsistencies in the current legal framework, including the Criminal Code, the Anatomy Act, and the Disability Act, which made it difficult to efficiently administer justice when the rights of persons with albinism were violated. The investigation further revealed that persons with albinism's ability to exercise their social, economic, and cultural rights is severely jeopardised by the attacks.

Based on the outcome of the investigation the Commission advised the State and other relevant parties to strengthen the security measures in place to prevent attacks against persons with albinism at community level, create a special housing fund for persons with albinism and their families, train police prosecutors, investigators, and magistrates on the changes made to the Anatomy Act and Penal Code under review and expand civic education and awareness campaigns at all societal levels. The Commission in addition called for immediate research to be conducted to identify the markets for the body parts of persons with albinism in Malawi and the criminal networks using these markets.[9]

Building on this the High Court of Malawi has also made recommendations to the state to strengthen legal provisions that protect persons with albinism and expediently investigate and prosecute crimes committed against this group. In the case of the Republic of Malawi v Kenneth Moses, the High Court of Malawi argued that the inquiry was not sufficiently thorough and that the state should seriously consider the veracity of the claims made by the accused. The state investigation and prosecution agency was reminded by the courts of the obligations and implications of its mandate in relation to persons with albinism.[10]

Developing and Monitoring the National Action Plan on Albinism in Malawi

The National Action Plan on Persons with Albinism in Malawi (NAP) received technical support from the Commission throughout its development and in monitoring its implementation. The National Response Plan 2014 on Albinism Atrocities was succeeded by the 2018 – 2022 National Action Plan on Persons with Albinism in Malawi (NAP) which was developed in February 2015 to facilitate effective and coordinated implementation of all national albinism and related programmes and activities.[11] The NAP categorically states that the Commission is crucial to the execution of tasks related to monitoring, reporting, and research on human rights.The Commission in 2021 conducted a monitoring exercise on the implementation of activities under the NAP. The monitoring exercise was aimed at providing feedback in terms of level of adherence to use of government resources and effectiveness of implementation of the NAP. The Commission in undertaking the monitoring exercise also sought to establish the extent of the implementation of the NAP by individual implementing institutions; identify and document strengths and weaknesses of the implementing institutions; identify gaps in the implementation of the NAP as a whole and record further interventions; and to assess the impact of the NAP activities on the human rights situations with albinism in Malawi. It identified amongst others the inability of staff from implementing institutions to properly understand and implement NAP, as well as delays and insufficient funding for NAP activities as some of the key hindrances to the effective implementation of the NAP. In addition, due to the inactivity of the National Level Albinism Technical Committee in the Office of the President and Cabinet, which was responsible for providing leadership and direction on NAP activities, there was insufficient participation, poor coordination, and communication amongst the various partners, including persons with albinism as rights holders. The lack of decentralisation of NAP financing in the Ministry of Health and Malawi Police services to the councils and limited ability of the albinism movement district committees to support the coordination and implementation of NAP at the district level were also identified as key weaknesses in the implementation of the NAP. The report recommended actions to be taken by the government, such as providing comprehensive orientation on NAP, considering increasing funding for implementation of NAP activities at district level, the Ministry of Health addressing the supply chain challenge that negatively impacted the availability of skin lotions in all health facilities, and decentralising NAP funds to local structures where the majority of persons with albinism live in order to directly support capacity development of albinism associations at district level.[12]

Monitoring Compliance with International and Regional Instruments

The Commission acts as an important intermediary in the preservation of the rights of persons with albinism under national, regional, and international human rights frameworks. It plays an important role in ensuring the enjoyment of human rights and fundamental freedoms. Malawi has signed and ratified several international and regional legal instruments that promote and protect the human rights of persons with albinism such as the International Covenant on Civil and Political Rights (ICCPR),[13] the International Covenant on Economic, Social and Cultural rights (ESCR),[14] the Convention on the Elimination of All Forms of Discrimination Against Women (CEDAW),[15] the African Charter on Human and Peoples' Rights (African Charter),[16] and the Protocol to the African Charter on Human and Peoples' Rights on the Rights of Persons with Disabilities in Africa (Disability Protocol),[17] which Malawi has signed but not yet ratified. The Government of Malawi ratified the Convention on the Rights of Persons with Disabilities (CRPD) in August 2009.

Malawi has a responsibility to advance, defend, and uphold the provisions of all these human rights instruments and to adopt all necessary legislative, administrative, and other means to bring the rights into effect. Malawi's HRC Act and the Constitution give the Commission the mandate to report to the President and Parliament on the progress made towards domesticating and implementation of human rights instruments ratified by the country. Additionally, the Commission is in charge of advocating for treaty ratification, reporting to treaty bodies, and integrating international law into national legislation.

The Commission has, taking into account Malawi's national, regional and international obligations been part of the task force to review and amend the Anatomy Act and Criminal Code in order to better ensure access to justice for persons with albinism in Malawi. A handbook for investigators, prosecutors, and magistrates on offences against persons with albinism was created as a result of the review process of the Acts. Aspects of criminal law, protocols for protecting and handling evidence, advice on how to formulate strong accusations against suspects, and the trial process are all included in the manual.[18] The Commission has trained over 90 investigators, prosecutors, and magistrates using the handbook to date.

Investigating Human Rights Violations against Persons with Albinism

The Commission investigated the death of Mr Buleya Lule whilst in police custody. Mr Lule was a main suspect in the murder of Goodson Faninzo, a boy with albinism. The Commission found following the investigation that Mr Lule had been subjected to severe, cruel, and inhumane treatment by police officers charged with his care resulting in his death and ordered the Director of Public Prosecutions to begin criminal proceedings against all police officers who are believed to have contributed to the events that resulted in the death of the accused while in police custody. The report demonstrated that Mr Lule's right to life, as guaranteed by international human rights agreements, was arbitrarily taken away by the police. The Commission called on the Police Department to ensure that human rights principles are maintained in all criminal investigations and prosecutions including those involving persons with albinism.

The Commission in its findings also made it clear that the state should concentrate on offering trauma counselling to the victim's mother, who also has a surviving child, a 12-year-old girl with albinism. The mother's testimony showed that she is still traumatised from the attack on her son and is unable to run her farm whilst simultaneously safeguarding her daughter. Her daughter's tuition is also too expensive for her to pay, and she is unable to make enough money to meet her basic necessities for food and clothing: 'I live in fear, I can't go to my garden as am afraid that people may take away the remaining child. I have no money to buy food, soap and school uniform for my daughter.'

The Commission had also received a complaint regarding Ian Muhamba, a young man with albinism, and the events leading up to his death. The complaint centred around Malawi Police Services' failure to handle the case with professionalism and ethical integrity. The investigation revealed that although the case was handled in compliance with Malawi Police Service Procedures in terms of case docket preparation, the investigators acted with egregious carelessness when they examined the victim's body and gathered evidence. The way the investigators handled the victim's remains exhibited a lack of professionalism, poor management, and unethical behaviour. Following the investigation, all police officers who handled the cases improperly were

demoted to general duties for flagrantly failing to perform their duties and were held accountable under the Code of Disciplinary Conduct for Police Officers. The Inspector General of Police and the Police Independent Complaints Commission were specifically urged by the Commission in its Media Statement dated 18 August 2021 on 'Condemnation of Harmful Practice Related to Accusations of Witchcraft and Ritual Attacks' to look into the way the responsible police officers handled Mr Muhamba's death. The Commission called for professionalism in the handling of all matters concerning killings and abductions of persons with albinism. To guarantee that those who commit human rights breaches are brought to justice, the Commission has improved its cooperation with other enforcement agencies in Malawi who are following its recommendations. The Commission has since created a complaint handling manual that offers instructions on how to handle a complaint or petition from a complainant with albinism from the time it is submitted until it is resolved.

Undertaking Human Rights Education and Public Awareness on Albinism

The Commission in light of its mandate to raise awareness of human rights including the rights of vulnerable groups such as children, the elderly, the illiterate, and people with disabilities has taken different actions to raise public awareness of the rights of persons with albinism including through public condemnation of the attacks alongside the President of Malawi, press statements, and awareness raising campaigns.

Conclusion

The Commission has a directorate on disability and elderly rights and has appointed in recent years two commissioners with disabilities for the first time in its history, one of whom has albinism. These appointments were a way of ensuring that the Commission more meaningfully considers the concerns of minority groups in all of its human rights programmes. Through self-representation in positions of leadership and public life, the appointment of a Commissioner with albinism has contributed to a rise in the visibility of persons with albinism and their issues within the Commission. Learning from the example of Malawi, National Human Rights Institutions across Africa should play a bigger part in systematically addressing the pervasive stigma and prejudice and accompanying human rights violations experienced by persons with albinism in the majority of African countries. Although the African Union adopted the Plan of Action to End Attacks and Other Human Rights Violations Targeting Persons with Albinism in Africa (2021 – 2031) in July 2019 as a regional policy framework, many African States have not taken the prescribed action to stop the violence and discrimination directed at this group. National Human Rights Institutions can play a role in encouraging governments to adopt National Action Plans on Albinism which will aid in ensuring that the rights, needs and priorities of persons with albinism are recognised and incorporated into the larger disability architecture of the country.

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REBELLING AGAINST THE STATUS QUO

Diana Rose Leonard

My name is Diana Rose Leonard, 26-years-old, from Tanzania. I am the only person with albinism in my family and clan on both my mother's and father's side. I have a sister, two brothers, and I am the last born. I was raised by my aunt (my mother's sister) and my mom who came to check on me from time to time. I grew up at Mwenge in Dar es Salaam. Currently I work as a Zonal Finance & Admin Officer at the Christian Social Services Commission (CSSC). Today I would like to share a piece of my life lessons learnt as a person with albinism.

Growing up, I was forbidden from playing outside during the day at home and school. I was confused and rebelled against that rule at school since there was no one watching. However, when I came back home my aunt would always notice that my skin had turned red and punish me. I remember this one occasion, a beach trip organised by my school, I was so excited to go. I went home and told my aunt and mom. To my surprise they told me I couldn't go, though I knew they could afford the payment. I didn't understand why they refused. I was crushed. I felt left out.

The day of the trip arrived and I went to school like ordinary days. I pleaded with my teacher to let me go with my friends. I had fun in the water, swings and slides and had a playful day with my friends. On the way back, I noticed that my body was boiling, and I was in pain. I got home and there were blisters all over my body. My aunt panicked, called my mom, and both asked me what happened. I had to come clean. I told them I had gone on the school trip. After the treatment of my blisters and sunburn, they took me to the Cancer Hospital at Ocean Road and we passed through different cancer wards. For the first time I saw people who had a similar skin colour to me. The difference was that they were covered with huge wounds which I was told were not curable.

'If you don't stop playing in the sun you will get sick, and we will have to leave you here!', my mom and aunt told me.

I was horrified with the thought of the blisters and sunburn that I had. 'What if I have cancer? What if I get those huge wounds?'

When I went back to school, I told my friends I couldn't play in the sun, or I would get sick. To my surprise they agreed to play under the shade of the tree. That moment was one of the most empowering in my life, it helped my confidence greatly. From that day I learnt to never shy away from being different, to embrace being different and to educate the people around me. I learnt that I don't have to try to fit in or try to be like anyone else, my uniqueness is what defines me.

However, for me being rebellious didn't stop there. After finishing my ordinary level studies, I refused to join a private school that my mom hoped I would attend. Instead, I opted to join the school the government selected for me to go to. The school was in Manyara region about 327 miles from Dar es Salaam. On the first day of term, I went with my mom but thereafter I told her I was happy going alone, and I would be fine, though she would call teachers to make sure that was the case. My life there was good. I made friends, some of whom are still in my life. I also learnt different agriculture activities.

After my Advanced Level studies, I joined the army for three months. By that time my mom didn't say a thing, I think she trusted that I was ready for whatever life threw at me. I can't lie, the first week of the army was very tough and I even regretted wanting to go but I gathered myself and decided to enjoy the learning experience. I ended up loving my experience there. I carry with me good memories and I made friends too. Two things I took from the army experience are patience and perseverance.

After graduating from the army, I joined Mzumbe University for a degree in Accounts and Finance. My brothers were the ones who inspired me to take this career path. Upon completion, I joined Under the Same Sun as an intern in the finance department in 2018. In April 2019, I was employed as an Accounting Assistant and the moment I got my contract I moved out from home where I was living with my sister who was relocated to Mbeya in 2020. I told my mom I was fine living alone. It was hard for her to grasp the idea, but I assured her that I could manage. To date I am living by myself.

Throughout my studies I was open to explaining my vision impairment to my friends. I used my hearing very well. If the teacher spoke, I jotted down notes which were very precise and sometimes requested by my friends, for mathematics formulas I asked to copy notes from my friends and I am thankful for them, because in each step they were very open to help me. The same can be said for my neighbours and family. Whenever I was with my sister if people called me names, she would put up a fight and scold them. Family has the power to give confidence.

They say that dreams come true and yes, I am living my dream and I am taking care of my mom and aunt, I am proud of the strong woman they made me into. I don't blame them for teaching me the hard way back then, there is no guidebook on being a parent and I understand they were just doing all they could and looking out for me.

***Diana Rose Leonard** is currently a Zonal Finance and Administration officer at Christian Social Service Commission. Her work entails daily posting of transaction, preparation of quarterly budget and variance reports both for internal and projects, also monitoring expenditures to be in line with what has been approved by donors and as per donor requirements. Previously, she worked with Under The Same Sun as an Accounts Assistant after completing her bachelor's degree.*

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