

“Fatal Discrimination”: Exploring Civil Society and State Perspectives on the Human Rights Situation of Persons with Albinism in Sub-Saharan Africa

Paul Chaney | ORCID: 0000-0002-2110-0436

Professor, School of Social Sciences, Cardiff University, Cardiff, Wales, UK
Chaney@cardiff.ac.uk

Received 10 December 2024 | Accepted 15 April 2025 |

Published online 15 May 2025

Abstract

This study explores civil society and state perspectives on the human rights status of persons with albinism (PWA), a rare genetic condition characterized by reduced or absent pigmentation of the hair, skin, and eyes. This analysis examines the “situated knowledge” in civil society organisations (CSOs) regarding the human rights situation of PWA in six sub-Saharan African states. The dataset comes from the Universal Periodic Review (UPR), the United Nations’ five-yearly treaty-monitoring programme. The findings reveal continuing serious human rights pathologies that PWA suffer, including widespread persecution, stigmatization, and murder owing to discrimination, superstition and witchcraft. Moreover, it shows governments’ policy responses have generally been inadequate; while some record progress, others deny or downplay PWA rights violations. The wider significance of this highlights the need for improved government action, including raising awareness of the issue and stricter monitoring of states’ UN treaty obligations.

Keywords

albinism – civil society – human rights – sub-Saharan Africa

1 Introduction

This study examines civil society and government perspectives on the human rights situation of persons with albinism in six African states. Albinism is a rare genetic condition with a worldwide incidence of one in 20,000 births. However, rates as high as one in 1,000 births can occur in parts of Africa. As Inena et al. explain, it is “characterized by reduced or absent pigmentation of the hair, skin, and eyes, as a result of deficient melanin production by melanocytes. As melanin is a photoprotective pigment that absorbs ultraviolet radiation, people living with albinism (PWA) ... are at increased risk of photo-damage and skin cancer” (2020, 1125). Recent analysis suggests that 90 percent of PWA with skin cancer die of the disease before the age of forty.¹ In order for a person to be affected by albinism, both parents must carry the gene. In that case there is a 25 percent chance that a child will be born with albinism at each pregnancy.

The reasons that this issue is deserving of attention are manifold. In the first instance, United Nations Human Rights Council Resolution of 23 March 2021 expressed “grave concern at the fact that attacks and widespread violence continue to be perpetuated against persons with albinism, in particular women and children, persons with disabilities and the elderly” (2021, 2). As a leading CSO observes, most “PWA in sub-Saharan Africa suffer from profound stigma and some from *fatal discrimination*” (Under the Same Sun 2013, 1, emphasis added) due to their distinctive appearance and the unfounded superstitions of others. As Hong et al. explain, “In Africa, the affected individuals have sandy coloured hair, white chalky skin and light brown or blue eyes” (2006, 4). Their markedly different visible appearance is “compounded by superstition, myths and a lack of understanding of albinism, [that] exacerbates their ‘otherness’ in the sub-Saharan context” (Taylor et al. 2019, 12). Children with albinism are particularly prone to abuse, persecution, stigmatization, abandonment, and marginalization. Not only is this because of their appearance, but they also suffer from disabilities associated with their condition such as impaired eyesight and sensitive skin. As Aceves explains, “Children are also subject to significant threats because their body parts are considered to have magical powers. ... [they] are exposed to severe incidents of violence, mutilation and murder. At times they become the target of witchcraft accusations, leading to the use of their body parts for ritual purposes” (2015, 574). Women with albinism are also threatened because some communities believe that having sex with a person with albinism can cure HIV/AIDS. Furthermore, women who give birth

1 <https://www.bbc.com/future/article/20170425-the-silent-killer-of-africas-albinos>.

to children with albinism are often rejected by their husbands and families because their children are viewed as bad omens or signs of infidelity.

Other reasons why the human rights situation of people with albinism is an appropriate focus for study include the fact that, as the UN notes, it has been an overlooked issue for many years “owing to a combination of deep misunderstanding of the condition of albinism, inadvertent exclusion from human rights advocacy, a paucity of best practices concerning the human rights of persons with albinism, and the absence of specific measures concerning PWA” (UN 2019, 1). PWA suffer from multiple, intersectional modes of human rights violations. They have been recognized as persons who face racial discrimination and stigmatization on the grounds of colour (CERD 2016, paras. 20–21) as well as disability (Brocco 2015). As the following analysis reveals, they are subject to further rights violations, including the right to life, education, healthcare, employment, standard of living, and access to justice.

The rights of PWA have also generally been overlooked in scholarly work. Extant studies variously refer to how “the paucity of information on the lives of children with albinism in Africa limits the development of appropriate interventions to support, empower and, most importantly, protect them at this time of danger in the region” (Taylor et al. 2019, 13); and “To date there is a paucity of research on the ... experiences of people with albinism” (Franklin et al. 2018, 2). In their scoping review of extant work on albinism, Reimer-Kirkhama et al. conclude “a key finding ... is the paucity of human rights discourse, despite abundant evidence about human rights violations. Of the 40 articles included in this scoping review, 27 (68 per cent) did not use the language of human rights, eight (20 per cent) made only limited reference to human rights language, and five (12 per cent) articles ... wrote substantively about the human rights violations for persons with albinism. ... [Yet] only two [Burke 2013; Burke et al. 2014] are published in peer-reviewed journals” (2019, 762). The other three were graduate essays. Accordingly, this study seeks to address this lacuna.

This paper examines the experiences and perceptions of civil society organisations (CSOs) regarding the human rights status of PWA in a purposive sample of six sub-Saharan countries: Tanzania, Mozambique, Malawi, Democratic Republic of the Congo (DRC), Kenya, and Uganda. The data source is CSOs’ submissions to the last two cycles of the Universal Periodic Review (UPR), the five-yearly monitoring mechanism of the United Nations (see Methodology below). At this juncture it is also germane to ask, “Why is civil society central to the present analysis”? In theoretical terms, examining civil society organisations’ views on human rights treaty implementation is appropriate because it engages with contrasting conceptualisations of civil society. While some define it as a strong, vibrant arena for associational life that acts as a watchdog for democracy (De Toqueville 1835/1840; Cohen and Arato 1993), others, such

as Gramsci (date), see it as a site of hegemonic and counterhegemonic struggle between citizens and ruling elites (Kumar 1993). In addition, allied to this, the strength of a civil society perspective lies in standpoint theory (Stoetzler and Yuval-Davis 2002) and CSOs' situated knowledge of PWA rights in sub-Saharan Africa. Standpoint is a qualitative technique designed to explore social actors' use of language, and the framings and tropes in their discourse. In epistemological terms, this derives from social constructivism and interpretivism. It is designed to directly convey the meanings and emotions associated with social actors' perspectives on different phenomena.

This study's overarching research question is "What are civil society organisations' perspectives on PWA rights violations in their UPR discourse?" The remainder of this paper is structured as follows. The next section outlines the research methodology. The research context in the case study countries is then summarised. This is followed by an analysis of civil society organisations' critical perspectives on PWA rights, as presented in their submissions to the last two UPR cycles. The conclusion discusses the significance of the study findings and future prospects regarding the human rights of persons with albinism.

2 Methodology

The case study countries were selected as a purposive sample based on their relatively high incidence of albinism, high level of attacks on PWA, and their geographical spread across Eastern, Southern, and Central Africa. The United Nations Universal Periodic Review (UPR) emerged in the wake of the 2006 UN General Assembly resolution (60/251). Its purpose is to monitor governments' UN human rights observance. In reviewing state practices, UN monitoring bodies also consider the views of those outside government. The associated policy framework is unambiguous. HRC resolution 5/1 of 18 June 2007 asserts that the UPR should "ensure the participation of all relevant stakeholders, including non-governmental organizations and national human rights institutions" (Cochrane and McNeilly 2013, 60). An indication of the reliability of this data source is the fact that the UPR registration and data submission process is that it forms the basis of all UN Working Group assessments of the human rights observance of all 180+ UN member states, and can be used in legal proceedings against rights-violating governments.

The civil society reports from the six case-study countries provide a rich data source that complements extant legal analyses and provides insight into the pursuit of participatory rights implementation. In total, the CSO dataset

comprised 390 reports submitted to the UPR. Here it should be noted that this figure underreports the extent of civil society input because many are joint submissions authored by broad alliances and networks of CSOs. For example, joint submission No. 11 in the 2016 UPR of Tanzania is a coalition of 103 civil society organizations. Because the current scientific method focuses on all CSO submissions to the last two UPR cycles in the case study countries it constitutes an example of corpus analysis (Vaughan and O’Keeffe 2015), a methodology concerned with the issues and framings in an entire dataset.

This study was operationalised using thematic analysis of the civil society UPR submissions (Fereday and Muir-Cochrane 2006; Neuendorf 2018) (see below). First, to generate initial themes regarding PWAs’ rights violations, a formative exploratory reading was undertaken of all of the submissions. The texts were subsequently reread. Through this iterative process twelve recurrent themes were identified related to violations and implementation issues around the human rights set out in major international human rights treaties such as the International Covenant on Economic, Social and Cultural Rights (ICESCR), and the International Covenant on Civil and Political Rights (ICCPR) (see “pathologies,” Table 2). Exemplar quotes were extracted and reproduced in the findings section of this paper.

TABLE 1 International treaty obligations offering protections to PWA, by country and year of ratification (“—” denotes not ratified)

Treaty	Congo (DRC)	Kenya	Tanzania	Uganda	Mozambique	Malawi
International Convention on the Elimination of Racial Discrimination (ICERD)	1976	2001	1972	1980	1983	1996
International Covenant on Economic, Social and Cultural Rights (ICESCR)	1976	1972	1976	1987	—	1993
International Covenant on Civil and Political Rights (ICCPR)	1976	1972	1976	1995	1993	1993

TABLE 1 International treaty obligations offering protections to PWA (*cont.*)

Treaty	Congo (DRC)	Kenya	Tanzania	Uganda	Mozambique	Malawi
Convention on the Elimination of Discrimination against Women (CEDAW)	1986	1984	1985	1985	1997	1987
Convention on the Rights of the Child (CRC)	1990	1990	1991	1990	1994	1991

SOURCE: UNITED NATIONS

This paper now focuses on the six case-study countries in turn. Each provides a succinct summary of the sociolegal context of PWA. The subsequent section turns to the study findings with analysis of civil society perspectives on the contemporary situation of PWA.

3 Sociolegal Context in the Case Study Countries

Following Human Rights Council resolution 28.6,² the report of the Independent Expert on the Enjoyment of Human Rights by Persons with Albinism makes it clear that “in international human rights law, persons with albinism hold the same fundamental rights as any other individual or group” (UN 2019, 2). As noted, these include the rights to life, physical integrity, liberty, security, equality and nondiscrimination, the highest attainable standard of physical and mental health and an adequate standard of living. They are set out in the Universal Declaration of Human Rights (UDHR) and a raft of subsequent UN treaties, including the Convention on the Rights of Persons with Disabilities (see Table 1). The Human Rights Council notes that “the last-mentioned instrument is of paramount significance for persons with albinism, in particular because of the duty set out therein to provide reasonable accommodation” (UN 2019, 2).

2 https://ap.ohchr.org/documents/dpage_e.aspx?si=A/HRC/RES/28/6.

Further protections for PWA extend from the African Union. From 2017 to 2021, both the African Commission on Human and Peoples’ Rights³ and the Pan-African Parliament⁴ endorsed the Regional Action Plan on Albinism in Africa (2017–2021)⁵ and the Plan of Action to End Attacks and Other Human Rights Violations Targeting Persons with Albinism in Africa (2021–2031).⁶ In addition, European Union resolution 2017/2868(RSP)⁷ calls for the EU to continue closely monitoring the human rights situation of PWAs in Africa, engaging with affected countries, and effectively supporting policies that uphold the rights of persons with albinism.

As the following analysis reveals, the sociolegal context in the case-study countries is characterised by increasing state repression of civil society, with clampdowns on freedom of expression and association. This compounds the difficulties that human rights defenders (HRD) face, including those concerned with upholding PWA rights. We now turn to the sociolegal context in each case-study country.

3.1 *Tanzania*

Estimates of the number of PWA vary. Out of a population of 59 million, the 2012 census reported there were 16,477⁸ PWA. In contrast, a leading PWA rights organisation indicates that there are at least 33,000 PWA (UTTS 2016). According to the census, one person in every 2,673 has the condition. The rural frequency is significantly lower than the urban frequency, and male incidence is markedly lower than for females (The United Republic of Tanzania 2014). Reflecting limited life expectancy, the census also revealed that 35 percent of PWA were aged thirty or over, and 25 percent were aged over forty years (Lund and Roberts 2018, 82–87). In addition to the protections under UN treaties, Article 13(1) of the Constitution provides that all persons are entitled, without any discrimination, to protection and equality before the law.⁹ Notwithstanding this, “since 2006 there have been 158 reports of violence against PWA in Tanzania, including 76 killings and 18 grave violations” (UTTS 2016, 1). However, limited reporting to the authorities means that the actual number of attacks and killings is likely to be much higher. The UN country

3 <https://www.achpr.org/>.

4 <https://au.int/en/pap>.

5 PAP.4/PLN/RES/05/MAY.18 https://www.chr.up.ac.za/images/centrenews/2018/files/2018_pap_resolution_on_persons_with_albinism.pdf.

6 <https://actiononalbinism.org/en/page/sfj6gs7s8kjd5f6c6zyhw7b9>.

7 <https://eur-lex.europa.eu/legal-content/EN/TXT/PDF/?uri=CELEX:52017IP0381&rid=10>.

8 <https://www.nbs.go.tz/index.php/en/>.

9 <https://rsf.org/sites/default/files/constitution.pdf>.

team reports that witchcraft is the main impetus for the killing and mutilation of persons living with albinism (UNCT 2019, 21). In the face of the ongoing atrocities, the UN Committee on the Rights of the Child (2015) expressed alarm at the killings of children with albinism for ritual purposes, and was concerned that prosecution of alleged offenders was hampered by fear of retribution and the reported complicity of some state authorities.

3.2 *Mozambique*

UN estimates suggest that there are 20,000 to 30,000 PWA in Mozambique out of a population of 30 million (IOM 2019, 6). Article 35 of the Mozambican Constitution guarantees “formal equality of all citizens before the law, regardless of colour, race, sex, ethnic origin, place of birth, religion, educational background, social status, or political preference.”¹⁰ The current sociopolitical situation in the country is a troubled one marked by armed conflict and repression. The war in Cabo Delgado province has intensified. As a recent study observes, in the last two years there has been “an escalation in the repression of the right to freedom of expression, characterized by intimidation, smear campaigns, harassment, arbitrary arrests, and prosecutions of journalists, human rights defenders and government critics” (Amnesty International 2021, 256). It is in this troubled context that United Nations Independent Expert on Persons with Albinism condemned the fact that

PWA are hunted and their body parts wanted; from head to toe, from cradle to grave, even their hair, nails and faeces are collected. ... General poverty in society also continues to threaten the work of the government on this issue. With body parts of persons with albinism allegedly priced by masterminds at millions to billions of Meticaï, the logical attraction of the gullible into this macabre trade needs no illustration. (United Nations Independent Expert 2016, para. 11)

3.3 *Malawi*

The Constitution of the Republic of Malawi guarantees protection from discrimination, *inter alia* in relation to colour, age, sex, and disability (Section 20).¹¹ Further protections for PWA are extended by the Disability Act (2012).¹² The country's 2018 Census is notable for providing information on

10 https://publicofficialsfinancialdisclosure.worldbank.org/sites/fdl/files/assets/law-library-files/Mozambique_Constitution_1990_%28as%20amended%29_en.pdf.

11 https://www.constituteproject.org/constitution/Malawi_2017.pdf?lang=en.

12 <https://malawilii.org/mw/legislation/act/2012/10>.

persons with albinism. It revealed that of the total population of 20 million about 0.8 percent, or 134,636 individuals, were PWA (UNHRC 2020, 11, para. 40). Over recent years there has been a sharp increase in human rights abuses against people with albinism, including abductions, killings, and grave robberies. At least eighteen people have been killed and five have been abducted and remain missing. A joint report by the Malawi Police and the Ministry of Justice and Constitutional Affairs documented at least 148 attacks (International Organization for Migration 2019, 3).

3.4 *Democratic Republic of the Congo (DRC)*

The DRC has a population of 79 million. Its constitution sets out a series of protections relevant to citizens with albinism (Articles 11 and 12).¹³ Notwithstanding this, discrimination, marginalization and violence beset the lives of people with albinism. As one PWA organisation observes, “To a great extent, Congolese with albinism do not enjoy rights to life, liberty and security of the person. Often, ... [they] are pejoratively called *Ndundu* (‘supernatural’) or *Tshitokatoka* (‘other’)” (UTTS 2017, 7). Discrimination against PWA is widespread and limits their ability to marry and obtain employment, health care, and education. They are “killed and their bodies disinterred from their graves and cut up for use in rituals meant to grant special power to anyone, from soccer teams to political campaigns” (USSD 2020, 39–40). A recent study found that “people living with albinism in the DRC experience a high rate of nonmelanoma skin cancers at a young age and additionally face a number of psychosocial challenges. Of 205 PWA [studied], 61 patients were diagnosed with skin cancer with a mean age of 26.5 years. A majority (88.5 per cent) had never used sunscreen, and 90.2 per cent spent 4 or more hours in the sun daily” (Inena et al. 2020, 1125). According to the UN (2019, 4), over recent years there have been fourteen recorded ritual killings, thirty-one attacks, one abduction, and nine grave robberies. As one PWA organisation stated, “These are reported cases only. ... The actual incidence of attacks is predicted to be much higher” (UTTS 2017, 6).

3.5 *Kenya*

Out of a total population of 55 million, there are over 3,000 officially registered PWA in Kenya, but more realistic estimates range from 5,000 to more than 15,000 (African Albinism Association 2021, 1).¹⁴ The Constitution of Kenya prohibits discrimination on the grounds of colour and disability (Arts. 27(4)

13 <https://constitutionnet.org/sites/default/files/DRC%20-%20Congo%20Constitution.pdf>.

14 <https://african-albinism.org/ons-werk/albinisme-in-kenia/>.

and 54(1)).¹⁵ Despite this, people with albinism are subject to widespread discrimination and often suffer from teasing and bullying. As one PWA organisation explains, “These names are often deeply derogatory and dehumanizing. ... [they] include ‘*dili*’ which means a monetary deal that can be earned from ritual killing of the PWA and ‘*Zeru Zeru*’ which refers to mystical or ghostlike beings” (Albinism Foundation of East Africa 2014, 4). According to the UN Independent Expert on Albinism, the discrimination and stigmatization of PWA is often perpetuated by friends, relatives, community members, or people in positions of power (UN Independent Expert on Albinism 2019, para. 22).

In 2013 Isaac Mwaura became the first Kenyan with albinism to join parliament, and his advocacy led to the earmarking of a budget line at the national level for persons with albinism.¹⁶ In 2015 the government announced a program for the purchase and distribution of sunscreen for persons with albinism. Despite these gains, as the following reveals, the government response to violations of PWAs’ rights has been inadequate. In 2015 there was no reference to PWA in the Kenyan Government’s UPR submission, yet the country received a number of recommendations on PWA from the UN Human Rights Council (No. 142.56, No. 142.70, and No. 142.145).¹⁷ Two years later the Committee on the Elimination of Racial Discrimination also recommended that the government take urgent and effective measures to protect PWA from violence, discrimination, and stigmatization (CERD 2017, para. 34). In 2018 the UN Independent Expert urged Kenya to create a comprehensive national action plan in line with the Regional Action Plan, “to end violence and violations against persons with albinism as recommended by the African Commission on Human and Peoples’ Rights” (UN 2018, 1).

3.6 *Uganda*

Out of a population of 47 million, it is estimated that 40,000 Ugandans have albinism (UTTS 2016, para. 9). However, as the current government itself admits, “there is no official data on the number, prevalence and national geographical distribution of persons with albinism in Uganda. As a consequence, persons with albinism have remained invisible and totally marginalized in government planning” (GoU 2020, 13, para. x). Human rights defenders describe the climate of fear that PWA in Uganda face. One said, “Here they kill us secretly and cut off

15 Constitution of Kenya 2010 <http://www.kenyalaw.org/lex/actview.xql?actid=Const2010> Accessed September 16, 2021.

16 <https://actiononalbinism.org/page/ixghrgubkxqvwwjnt912fyldi>.

17 https://www.upr-info.org/sites/default/files/document/kenya/session_21_-_january_2015/recommendations_and_pledges_kenya_2015.pdf.

some of our body parts for ritual purposes.”¹⁸ Another explained how the dangers can inhibit data collection: “We do not follow up on cases of missing persons for our own security” (Under the Same Sun (UTSS) (2016), 2).¹⁹ Such fear reflects the wider, prevailing social context. A contemporary report notes, “The authorities continued to restrict the rights to freedom of expression, peaceful assembly and association ... even amid a pandemic, attacks on human rights defenders and opposition activists did not relent. This was particularly the case in countries that held or headed towards elections, like ... Uganda” (Amnesty International 2021, 369). A recent study of PWA in Uganda summed up the situation: “Most people with albinism endure life-long, systemic discrimination and violence. Even those who manage to overcome social and economic barriers, still encounter actual or potential risk on a day-to-day basis. Thus, there is still a great deal to be done” (Bradbury Jones et al. 2018).

Attention now turns to the critical views of civil society organisations, as set out in their UPR discourse.

4 The Perspectives of Civil Society Organisations on PWA Rights Violations

First, in terms of the total level of attention to PWA (or “issue salience”) in the CSO UPR submissions of the six countries over the past two cycles, 80 per cent of references (quasisentences) to albinism were made in the last cycle. This lends credence to Clark and Beale’s observation that following historical neglect, “the last few years have seen unprecedented mobilization to confront this issue in Tanzania and across Africa” (2018, 262). The different types of human rights violation faced by PWA as identified by CSOs in their UPR discourse is now analysed. The different rights pathologies and the legal basis of these treaty violations are set out in Table 2.

4.1 Violence

Violations of Article 3 of the UDHR was a prominent rights pathology in the UPR discourse (Table 2). The comments from civil society organisations are typified by “Twelve attacks have been documented against PWA in Kenya. Some of them qualify as torture given the extreme pain inflicted on the victim

18 The Africa Report, “Uganda: Albinos seek government protection.” September 10, 2012, <http://www.theafricareport.com/East-Horn-Africa/uganda-albinos-seek-government-protection.html#ixzz3zeBLIU00> Accessed August 20, 2021.

19 Under the Same Sun (UTSS) (2016) Ugandans with Albinism, Dar Es Salaam: UTSS.

TABLE 2 Human rights violations against PWA identified in civil society organisations’
UPR discourse across the case-study countries

Pathologies – Nature of Rights Violations	Examples of the Legal Basis of UN Treaty Violations‡
Violence/Killing/Murder	UDHR† Art. 3. “Everyone has the right to life, liberty and the security of person.”
Strengthening PWA rights	UDHR, Art. 29. “Everyone is entitled to a social and international order in which the rights and freedoms set forth in this Declaration can be fully realized.”
Health (inc. sunscreen, skin cancer)	ICESCR† Art. 12. “The right of everyone to the enjoyment of the highest attainable standard of physical and mental health.”
Trafficking/trade in body parts	ICCPR† Article 8. 1. “No one shall be held in slavery”/UDHR Art. 3.
Access to justice (including police investigation and underreporting)	UDHR Art. 8. “Everyone has the right to an effective remedy by the competent national tribunals for acts violating the fundamental rights granted him (sic) by the constitution or by law.” Art. 10 “Everyone is entitled in full equality to a fair and public hearing by an independent and impartial tribunal, in the determination of his rights.”
Discrimination against PWA	ICERD† Art.1 “Art. 1. [prohibiting] discrimination [this] shall mean any distinction, exclusion, restriction or preference based on race, colour”; ICRPWD† Art 1. “The full and equal enjoyment of all human rights and fundamental freedoms by all persons with disabilities, and to promote respect for their inherent dignity.”

‡ For reasons of brevity one or two UN treaties are used to illustrate the legal basis of each type of rights violation. Violations often relate to multiple treaties (see Table 1).
† UDHR – Universal Declaration of Human Rights; ICESCR – International Covenant on Economic, Social and Cultural Rights; ICCPR – International Covenant on Civil and Political Rights; ICERD – International Convention on the Elimination of Racial Discrimination; ICRPWD – Convention on the Rights of Persons with Disabilities.

TABLE 2 Human rights violations against PWA (*cont.*)

Pathologies – Nature of Rights Violations	Examples of the Legal Basis of UN Treaty Violations‡
PWAs’ access to education/schooling	UDHR Art. 26. “Everyone has the right to education.”
Awareness raising of PWA rights (including via education curriculum)	UDHR, Preamble. “Every individual and every organ of society, keeping this Declaration constantly in mind, shall strive by teaching and education to promote respect for these rights and freedoms.”
Witchcraft, magic, superstition as a basis for harm to others	UDHR Art. 3. “Everyone has the right to life, liberty and the security of person.”
Resources to promote PWA rights (inc. training of those working with PWA)	ICESCR, Art. 2. “Each State Party to the present Covenant undertakes to take steps ... to the maximum of its available resources, with a view to achieving progressively the full realization of the rights recognized in the present Covenant by all appropriate means.”
Representation/participation of PWA in decision-making	ICERD, Art. 5. “Political rights, in particular the right to take part in the Government as well as in the conduct of public affairs at any level.”
Employment of PWA	UDHR Article 23. “Everyone has the right to work.”

and the intent of the perpetrator” (UTTS Kenya 2014, para. 33). Many give gruesome details of individual cases, such as “His murderer was a rich businessman who had been told by ‘a medicine man’ that killing a person with albinism was a path ‘to get rich fast’ ... In another case, ... [the perpetrator] killed ... [the victim] with a metal bar and a hoe handle before chopping off his hands and legs” (Amnesty International 2020, 7). According to another account, the victim “was abducted by three men. Her body was found the following morning with her legs, genitals, breasts and hands removed” (UTTS Kenya 2015, 7). The discourse also gives graphic accounts of those that survive attacks such as “A seven-year-old boy with albinism in Embu, Kenya managed to escape relatives who tried to sell him for ritual purposes. He was kidnapped by his uncle together with other relatives who attempted to take off to an unknown

destination where they were to meet the buyers. The boy said that the kid-nappers threw him out of the window of a moving vehicle when he screamed for help and was rescued” (Joint submission of Albinism Foundation of East Africa 2015, 8).

4.2 *Strengthening the Rights of PWAs*

CSOs repeatedly highlighted the need to extend existing legal protections for PWA. One urged the government to “develop a national action plan, institutional policies and legal framework to criminalize violence against persons living with albinism” (FMMRPU 2–21, 3), and another said that “the government of Uganda ... should institute special protection measures for children with Albinism” (UCRNN – Uganda Child Rights NGO Network 2011, 4). Others registered frustration that governments had not acted on earlier UPR recommendations, such as “Mozambique received the following recommendations from the previous cycle, and all were noted/not accepted: Strengthen mechanisms to prohibit discrimination against vulnerable groups, including persons with albinism” (Young Feminist Movement of Mozambique 2021, 2). The CSO UPR discourse also highlights how increasing state regulation and repression of civil society is hampering their advocacy for strengthening PWA rights across the case-study countries. For example, one complained that “the Non-Governmental Organizations Registration (Amendment) Act 2006²⁰ has made the work of NGOs more difficult. The Government of Uganda should consider a streamlined, less onerous process, or the de-regulation of NGOs” (UTTS 2016, 11).

4.3 *Health*

The civil society discourse makes manifold references to the lack of appropriate health services for PWA, such as “In the DRC, there is no specific health coverage for people with albinism” (ACVDP et al. 2019, 3); and “Kenya, for instance, does not have a rescue centre for PWAs, Albinism health research, PWA sunscreen production centre, availability of hats and eye care glasses for PWAs ... and [there are] no reliable data on PWAs” (Albinism Society of Kenya 2020, 5). The CSOs’ UPR submissions explain that the lack of healthcare has a number of causes: poor infrastructure, lack of preventive information from primary healthcare workers, and the cost of sunscreen products. As Rao notes, affordability is a key problem: “Many of those living with the condition cannot afford badly needed sunscreen and protective clothing ... a bottle of sunscreen that

20 https://www.icnl.org/research/library/uganda_ngoreg2006/.

lasts for two weeks sells for about \$15 in Tanzania, a country where most people live on less than \$1.50 a day” (2018, 2). The civil society discourse also highlights the consequences of poor health protection: “With no natural sun protection, fatal skin cancer will claim the vast majority of Africans with albinism before they reach 30 to 40 years of age. There is little awareness of the need for sun protection and sunscreen is not commonly available or affordable in most African countries” (UTTS 2016, 8).

A further strand of the discourse focuses on healthcare workers’ skills: “The government should ensure shelter staff are trained in the low vision needs of children with albinism. Staff must know that the majority of children with albinism have sufficient visual acuity to read print and should not be forced to learn Braille. ... Low vision training will also ensure that staff is able seek support from authorities, such as low vision devices or tinted sunglasses” (UTTS Tanzania 2016, 3). Others complain about the standard of the little amount of state healthcare that is available: “Persons with albinism are unable to access quality health care services, including cancer services ... the last allocation of government-issued sunscreen lotion given to the Association of Persons with Albinism to distribute had expired, showing disregard for the health and well-being of persons with albinism” (DIWA – Disabled Women in Africa & Women Enabled International 2020, 5).

4.4 *Trafficking and Trade in Body Parts*

Trade in body parts was a prominent rights pathology in CSO discourse. For example, one of the principal “concerns of the Mozambican civil society organizations ... [is the] rising tide of trafficking in organs and body parts, as well as people living with albinism. [A key failing is] the absence of a specific law that punishes trafficking in organs and body parts, as well as people living with albinism” (Liga dos Direitos Humanos, Lutheran World Federation, and Liga de ONG’s de Moçambique 2016, 7). Another responder explained the economics of the macabre trade and the huge financial incentives involved: “Attacks go unreported because the body parts of PWA are sold on a black market for thousands of dollars. Specifically, a limb can be sold for thousands of US dollars and a ‘complete set’ of body parts goes for upwards of \$75,000. In a country where the average annual income (using GDP per capita) is roughly \$1,800 US dollars per year, the only people that can afford such prices are likely the rich elite who are also better placed to purchase the silence of perpetrators and police alike” (UTTS Kenya 2015, 12). CSOs also provide powerful vignettes of individual trafficking cases. For example, “a near death experience occurred for a girl with albinism when her father was caught in the act and charged with human trafficking. The arrest revealed that he was in the process of selling his daughter to

a Tanzanian buyer for an undisclosed amount of money” (Joint submission of Albinism Foundation of East Africa 2015, 8). A further core issue is the endurance of this rights violation despite manifold attempts to address it: “In 2017, Mozambique hosted the first ever forum aimed at combatting human trafficking of people with albinism. ... Despite this forum being held, albino children in Mozambique are still in danger” (ECLJ 2021, 4).

4.5 *Access to Justice*

UDHR Article 8 violations are a further transgression of rights. One strand of this discourse highlights institutional ableism, or systemic discrimination (Chaney 2021). For example, “Current policies and practices in Malawi fail to address the specific barriers persons with disabilities – particularly women with disabilities – face in accessing justice. Principally, the government has failed to implement key provisions of the Disability Act” (DIWA – Disabled Women in Africa & Women Enabled International, 2020, 5). Also, “The plight of persons with albinism remains particularly desperate ... victims are often discriminated against throughout whole judicial process” (Franciscans International, ECOSOC, Edmund Rice International and Marist International Solidarity Foundation 2016, 5).

Even when cases come to trial, justice is denied because of unsuccessful outcomes. For example, “of the 72 murders of people with albinism documented in the United Republic of Tanzania since 2000, only five cases are known to have resulted in successful prosecutions” (Mtandao wa Vikundi Vya Wakulima Tanzania, Tanzania Home Economics Association and et al Meru Community Bank – Arusha. 2016, 4). In addition, “only 30 per cent of investigations into reported attacks against people with albinism have been concluded” (Amnesty International 2020, 3).

A third issue was police failure to fully investigate PWA rights violations. For example, UTTS Kenya recommends increasing efforts to “put an end to the various forms of crimes affecting PWA, strengthen the legal response to such crimes and bring perpetrators to justice through prompt and impartial investigations” (UTTS Kenya 2015, para. 45). A fourth strand of the discourse stemmed from the sociolegal situation of PWA across the case study countries. As analysed above, a common trend across case-study countries was state repression of civil society. The civil society UPR discourse on access to justice reflects this. A number of CSO submissions to the UPR are anonymous owing to fears about safety. For example, one states it “was written by and concluded after close consultation and input by 10 grassroots NGOs in Tanzania. Their names are known. However, the current environment for civil society in Tanzania is not safe enough for them to have their names included in this report” (Anon

Joint submission 2021, 2). In a similar vein, this CSO submission describes the current situation in Malawi: “Recent efforts by persons with albinism to assert and defend their human rights through peaceful protest has been met with violence and arbitrary arrest by the State” (Association of Persons with Albinism 2020, 4).

4.6 *General Discrimination against PWA*

A core issue in the civil society UPR discourse is general discrimination against PWA, such as “People with albinism, people with disabilities, and ethnic and racial minorities continue to suffer discrimination and violence in various public institutions and in their daily lives. Mozambique should: ... implement a policy of zero tolerance against discrimination of minorities” (Coalition of Mozambican Civil Society Organizations 2021, 4), and “Persons with albinism in the country continue to suffer from stigma and discrimination (UTTS Kenya 2014, 5).

4.7 *PWAs’ Access to Education*

One strand of the CSO discourse on education underlines the need for reasonable adjustments or accommodations for PWA, as required by ICRPWD. One CSO demanded that the government “build schools adapted for vulnerable children, including those living with disabilities and albinism to facilitate their learning, by 2020” (LIZADEEL, SMM, ACJDH and ACVDP. 2020, 3). Another explains, “In the education system, children with albinism have difficulty integrating, especially because of vision difficulties (these children do not see well the teacher’s writings that are on the board) and [are subject to] the mockery of other children” (Association des Femmes Avocates de la DR Congo 2020, 3). Others illustrate how “the real threat of violence against persons with albinism inhibits their equal participation in everyday life activities including the attendance of school, employment and accessing healthcare and other social services” (Association of Persons with Albinism 2020, 4).

4.8 *Awareness Raising*

As Mihr (2009) observes, awareness raising is a key process in upholding international treaty obligations. In their UPR submissions CSOs repeatedly called on the government to promote general awareness of PWAs’ rights. These included “Conduct community education programs to debunk superstitious beliefs that body parts of people with albinism bring luck in business and politics” (Amnesty International 2020, 4) and “Launch a nationwide education and awareness campaign to prevent stigmatization of persons with albinism to ensure their security” (JS11, a coalition of 103 civil society organizations

in Tanzania 2016, 5). Others highlight states' failure to address previous UPR recommendations on this issue: "Previously accepted UPR recommendation: Launch a nationwide education and awareness campaign to prevent stigmatization of persons with albinism to ensure their security and facilitate their equal access to education and employment" (UTTS 2016, 7). Yet, as this CSO proceeds to note, "Tanzania's educational campaign efforts have been modest given the scale of the problem ... government has resources, authority and infrastructure unavailable to civil society and should be leading and funding such campaigns" (UTTS 2016, 7).

A further dimension to awareness raising is media reporting of the rights violations of PWA. The CSO UPR discourse resonates with the wider international literature on a global trend of state repression of the civil sphere (Nazarski 2017). For example, in Malawi one CSO complained that "in March 2019, a journalist with ... [a named] Broadcasting Station ... was assaulted and detained by the police for covering protests staged by the Association of Persons with Albinism in Lilongwe. In February 2019, BBC journalists investigating a series of mysterious murders in Malawi were attacked in Karonga by an angry mob who confiscated their equipment and damaged one of their two vehicles. In July 2018, two government-linked officials assaulted newspaper columnist ... for his criticism of the Mutharika administration" (CIVICUS 2020, 8).

4.9 *Witchcraft, Magic, and Superstition*

A further topic of the CSO discourse condemns states' failure to fully address witchcraft and superstition as causes of PWA rights violations. For example, one observed:

The plight of persons with albinism remains particularly desperate as local beliefs have cemented a perception that they are unnatural or even "cursed" individuals, which has created almost unshakeable stigma and discrimination against this minority of the population. Individuals affected are sometimes rejected by their families, avoided by their peers and stigmatised throughout life, from the schoolyard to the courtroom. ... Criminals, in the guise of traditional healers, encourage the notorious mutilations of people with albinism due to their supposed "magical properties." (Mtandao wa Vikundi Vya Wakulima Tanzania, Tanzania Home Economics Association and et al Meru Community Bank – Arusha, 2016, 7)

Others pointed to the difficulties of addressing the issue: "Most attacks against PWA go unreported due to the 'code of silence' and overall secretive nature of witchcraft" (UTTS Kenya 2014, 3). In highlighting the general

failure of governments’ policy responses, CSOs underlined how demand for PWA body parts had also increased, compounding the problem: “There has been an unprecedented rise in witchcraft-related killings of persons with albinism in recent years and relatively in Kenya, because their body parts are used in potions sold by witchdoctors ... three men were convicted of killing a 14-year-old boy with albinism and severing his legs in order to sell them for witchcraft purposes” (Albinism Society of Kenya 2020, 8).

4.10 *Resources to Promote PWA Rights*

The inadequacy of resources that governments allocate to promote PWA rights is a further theme in the civil society discourse. For example, “The authorities [in Malawi] only started to prosecute cases of murder of people with albinism in 2019 due to inadequate resources and staff shortages in the office of the Director of Public Prosecutions and the legal aid board” (MHRC 2019, 3), and “The Multi-sectorial Plan to Fight Violence against persons with albinism was drafted. However, there are still challenges ... in the provision of budget for its implementation” (Mozambican Forum of Disabled Persons Organisations 2021, 7). A further topic of the resources discourse concerns human capital, or the skills of those working with PWA. For example, “In Tanzania there are shelters for internally displaced persons with albinism. ... The government should ensure shelter staff are trained in skin cancer awareness, identification and prevention and make them aware of its deadly impact on children with albinism” (UTTS Tanzania 2016, 12).

4.11 *Representation and Participation in Decision-making*

Article 5 violations of ICERD were a further key issue (“Political rights, in particular the right to take part in the Government as well as in the conduct of public affairs at any level”). One cause is institutional ableism. As one CSO noted, “structural barriers prevent their participation in society on an equal basis with others” (UTTS Tanzania 2016, 3). The civil society discourse also underlines the importance of descriptive representation, that states elected representatives should be typical of the class of people that they represent (Mansbridge 1999). As Philips asserts, this is “the politics of presence” – rather than having third-party representatives, PWA should hold elected office. One CSO observed: “The Government of Uganda should create a special parliamentary representative for people with albinism ... the Uganda Albino Association (UAA) reports that persons with albinism have not been able to achieve adequate representation via the Disabilities Members of Parliament, in part because of low awareness of albinism being a disability” (UTTS 2016, 9).

Although long ignored, the UPR discourse suggests that the issue is climbing up in the political agenda. The Albinism Foundation of East Africa notes that “while the constitution of Kenya enshrines affirmative action ... PWA tend to be passed over for persons with other types of disabilities as most employers, government included, do not regard them as properly belonging to the category of persons with disabilities” (2014, 2). Other CSOs used their UPR submissions to ask searching questions of the political establishment including: “Questions for the Government of Uganda. ... How will the government improve the representation of Ugandans with albinism in law, Parliament and in government?” (UTTS Uganda 2016, 5) and “Questions for the Government of Tanzania. ... How is the right to child participation respected when children are not consulted about transportation to shelters for internally displaced persons with albinism?” (UTTS Tanzania 2016, 12).

4.12 *Employment*

UDHR Article 23 violations (“Everyone has the right to work”) were a further core issue of the civil society UPR discourse. Employment is of pivotal importance to PWA. As one CSO put it, “Pervasive myths and misconceptions about their condition relegates most of them into isolation that locks them in a vicious cycle of poverty” (UTTS Kenya 2014, 2). Labour market exclusion is a key part of this downward spiral. As another CSO noted, “Persons with albinism also suffer double discrimination in the field of employment as employers assume that their capacity to deliver within the workplace is below par. Sometimes they may also be subject to conditions that are hostile to their condition such as working directly under the hot sun or bright light which puts them at risk of skin cancer and /or further eye impairment” (Albinism Foundation of East Africa 2014, 4).

5 Conclusion

The present findings reveal how, over the last UPR cycle, PWA rights have risen in the political agenda after centuries of suffering and marginalisation. The latest UPR data provide evidence of progress, but also a troubling litany of continuing rights violations of PWA, complicity of ruling elites, as well as a general failure to introduce reasonable accommodations as required by the CRPD. They also signal widespread civil society frustration at the lack of progress since the last UPR. The emerging issues that the CSO discourse highlights do not make comfortable reading for the region’s political elites. They include inadequate

funding of PWA rights initiatives, systemic discrimination, disenfranchisement and marginalisation in decision-making, poor levels of descriptive representation, extensive breaches of welfare rights, and denial of access to justice. They also expose government failure to tackle pernicious beliefs about witchcraft and PWA, thus leading to further torture, violence, and murder.

The current analysis also underlines that the present is a transition point. The appointment of Ikponwosa Ero in 2015 as UN Independent Expert on the Enjoyment of Human Rights by Persons with Albinism, as well as the African Union Regional Action Plan on Albinism in Africa (2017–2021) have kick-started long-overdue reforms and underpinned the political reprioritisation of PWA rights. In addition, the last UPR period has seen the emergence of comprehensive action plans on PWA rights in some, but not all, of the case-study countries. Their implementation was severely disrupted by the COVID-19 pandemic. Consequently, it is too soon to judge their impact. On face value, they appear to be potentially transformative instruments since they often include measurable targets and time frames, allocated budgets, and ambitious conceptual approaches such as mainstreaming PWA rights. However, over the coming years their implementation is likely to be shaped by fluctuating political will and budgetary constraints. Moreover, attention to the wider sociopolitical context does not bode well. As this study reveals, increasing government repression of civil society is evident in all six countries, making it harder for CSO mobilisation and HRDs’ advocacy of PWA rights.

Earlier studies have highlighted limitations in the effectiveness of the United Nations Universal Periodic Review process (Cole 2015; Kalin 2015; Terman and Voeten 2018), notably the general absence of compulsion for the state under review to accept and fully respond to UPR recommendations. This resonates with the present study because, as noted, the analysis shows that governments were slow to respond to earlier UPR cycle recommendations, and a significant increase in attention to PWA rights only occurred in the last cycle. Yet it is argued that the UPR is a unique and invaluable mechanism in the face of a global trend of state repression of civil society. In large measure, the prospects for persons with albinism will depend on governments’ willingness to listen to the situated knowledge of civil society organisations regarding PWAs’ rights, as set out in this study. This should be accompanied by increased descriptive representation of PWA in all decision-making forums. In the face of widespread and ongoing violations, including violence, murder, and state repression of the civil sphere, the present evidence suggests that the international community needs to redouble its efforts to uphold the human rights of persons with albinism.

Acknowledgement

The author would like to gratefully acknowledge grant funding from the Economic and Social Research Council under Awards No: ES/S012435/1 and UKRI264, which enabled this study to be completed.

References

- Aceves, William. 2015. "Two stories about skin color and international human rights advocacy." *Washington University Global Studies Law Review* 14.4, 563–584.
- ACVDP LIZADEEL, SMM and ACJDH. 2019. *Non-Governmental Organization (NGO) Report to the United Nations Universal Periodic Review*. Geneva: UN.
- Albinism Foundation of East Africa. 2014. *The human rights of Persons with Albinism in Kenya*. Nairobi: AFEA.
- Albinism Society of Kenya. 2020. *Non-Governmental Organization (NGO) Report to the United Nations Universal Periodic Review*. Geneva: UN.
- Amnesty International (Malawi). 2020. *Non-Governmental Organization (NGO) Report to the United Nations Universal Periodic Review*. Geneva: UN.
- Amnesty International. 2021. *Amnesty International Report 2020/21: The State of the World's Human Rights*. London: Amnesty International.
- Anon Joint submission (Tanzania). 2021. *Non-Governmental Organization (NGO) Report to the United Nations Universal Periodic Review*. Geneva: UN.
- Association des Femmes Avocatess de la DR Congo. 2020. *Non-Governmental Organization (NGO) Report to the United Nations Universal Periodic Review*. Geneva: UN.
- Association of Persons with Albinism. 2020. *Non-Governmental Organization (NGO) Report to the United Nations Universal Periodic Review*. Geneva: UN.
- Bradbury-Jones, Caroline, Peter Ogik, Jane Betts, Julie Taylor, and Patricia Lund. 2018. "Beliefs about people with albinism in Uganda: A qualitative study using the Common-Sense Model." *PLoS ONE* 13.10, e0205774.
- Brocco, Giorgio. 2015. "Labelling albinism: language and discourse surrounding people with albinism in Tanzania." *Disability & Society* 30.8, 1143–1157.
- Burke, Jean. 2013. "Media Framing of Violence against Tanzanians with Albinism in the Great Lakes Region: A Matter of Culture, Crime, Poverty and Human Rights." *The Australasian Review of African Studies* 34.2, 57–77.
- Burke, Jean, Theresa Kaijage, and Johannes John-Langba. 2014. "Media Analysis of Albino Killings in Tanzania: A Social Work and Human Rights Perspective." *Ethics and Social Welfare* 8.2, 117–134.
- Chaney, Paul. 2021. Civil Society, Rights and Welfare: Exploring the Implementation of the Convention on the Rights of Persons with Disabilities in the Commonwealth of Independent States. *Europe-Asia Studies*, 74.5, 734–759.

- CIVICUS. 2020. *Non-Governmental Organization (NGO) Report to the United Nations Universal Periodic Review*. Geneva: UN.
- Clarke, Sam, and Jon Beale. 2018. "Albinism and Social Marginalization." In J. Kromberg and P. Manga (eds.), *Albinism in Africa: Historical, geographic, medical, genetic, and psychosocial aspects*. London: Academic Press, 257–269.
- Coalition of Mozambican Civil Society Organizations. 2021. *Non-Governmental Organization (NGO) Report to the United Nations Universal Periodic Review*. Geneva: UN.
- Cochrane, Leanne, and Kathryn McNeilly. 2013. "The United Kingdom, the United Nations Human Rights Council and the first cycle of the Universal Periodic Review." *The International Journal of Human Rights* 17.1, 152–177.
- Cohen, Jean, and Andrew Arato. 1993. *Civil Society and Political Theory*. Cambridge, MA: MIT Press.
- Cole, Wade. 2015. "Mind the Gap: State Capacity and the Implementation of Human Rights Treaties." *International Organization* 69.2, 405–441.
- Committee on the Elimination of Racial Discrimination. 2016. *Concluding observations on the combined fourth to eighth periodic reports of South Africa*. New York: UN CERD/C/ZAF/CO/4-8. <https://undocs.org/CERD/C/ZAF/CO/4-8>.
- DIWA – Disabled Women in Africa & Women Enabled International. 2020. *Non-Governmental Organization (NGO) Report to the United Nations Universal Periodic Review*. Geneva: UN.
- ECLJ. 2021. *Non-Governmental Organization (NGO) Report to the United Nations Universal Periodic Review*. Geneva: UN.
- Fereday, Jennifer, and Eimear Muir-Cochrane. 2006. "Demonstrating rigor using thematic analysis: a hybrid approach of inductive and deductive coding and theme development." *International Journal of Qualitative Methods* 5.1, 80–92.
- Franciscans International, ECOSOC, Edmund Rice International and Marist International Solidarity Foundation. 2016. *Non-Governmental Organization (NGO) Report to the United Nations Universal Periodic Review*. Geneva: UN.
- FMMRP Mozambique. 2020. *Non-Governmental Organization (NGO) Report to the United Nations Universal Periodic Review*. Geneva: UN.
- Franklin, Anita, Patricia Lund, Caroline Bradbury-Jones, and Julie Taylor. 2018. "Children with albinism in African regions: Their rights to 'being' and 'doing.'" *BMC International Health and Human Rights* 18.2, 132–141.
- Hong, Esther S., Hajo Zeeb, and Michael H. Repacholi. 2006. "Albinism in Africa as a public health issue." *BMC Public Health* 6, 212.
- Inena, Gaylord, Brian Chu, Dadi Falay, Bambale Limengo, Ibanda Matondo, Abisa Bokanga, Carrie Kovarik, and Victoria L. Williams. 2020. "Patterns of skin cancer and treatment outcomes for patients with albinism at Kisangani Clinic, Democratic Republic of Congo." *International Journal of Dermatology* 59, 1125–1131.

- International Organization for Migration. 2019. *Situation Analysis on the Human Rights and Protection of Persons with Albinism in Mozambique with a Special Focus on Human Trafficking*. Maputo: International Organization for Migration.
- Kalin, Walter. 2015. "Ritual and Ritualism at the Universal Periodic Review." In H. Charlesworth and E. Larking (eds.), *Human Rights and the Universal Periodic Review*. Cambridge: Cambridge University Press, 25–42.
- Kawire Wabwire, Audrey. 2019. "Tanzania Should Move Ahead with an Albinism Protection Plan." *The Citizen*. 23 April. <https://www.hrw.org/news/2019/04/23/tanzania-should-move-ahead-albinism-protection-plan>.
- Kumar, Krishan. 1993. "Civil Society: An inquiry into the usefulness of an historical term." *British Journal of Sociology* 44.3, 375–395.
- Libbrecht, Liselotte, Bart Maddens, and Wilfried Swenden. 2009. "Issue salience in regional party manifestos in Spain." *European Journal of Political Research* 48, 58–79.
- Liga dos Direitos Humanos, Lutheran World Federation, and Liga de ONG's de Moçambique. 2016. *Non-Governmental Organization (NGO) Report to the United Nations Universal Periodic Review*. Geneva: UN.
- LIZADEEL, SMM, ACJDH and ACVDP. 2020. *Non-Governmental Organization (NGO) Report to the United Nations Universal Periodic Review*. Geneva: UN
- Lund, Patricia, and M. Roberts. 2018. "Prevalence and Population Genetics of Albinism: Surveys in Zimbabwe, Namibia, and Tanzania." In Jennifer Kromberg and Prashiela Manga (eds.), *Albinism in Africa*. City: Academic Press, 81–98.
- Mansbridge, Jane. 1999. "Should Blacks Represent Blacks and Women Represent Women? A Contingent 'Yes.'" *The Journal of Politics* 61.3, 628–657.
- Masina, Lameck. 2021. "Malawi Struggles to End Attacks on People With Albinism." *Voa News*, August 21. https://www.voanews.com/a/africa_malawi-struggles-end-attacks-people-albinism/6209802.html.
- Mihr, Anja. 2009. "Global Human Rights Awareness, Education and Democratization." *Journal of Human Rights* 8.2, 177–189.
- Mtandao wa Vikundi Vya Wakulima Tanzania, Tanzania Home Economics Association and Meru Community Bank – Arusha. 2016. *Non-Governmental Organization (NGO) Report to the United Nations Universal Periodic Review*. Geneva: UN.
- Nazarski, Eduard. 2017. "SIM Peter Baehr Lecture: Shrinking space for civic space: The countervailing power of NGOs." *Netherlands Quarterly of Human Rights* 35.4, 272–281.
- Phillips, Anne. 1995. *The Politics of Presence*. Oxford: Clarendon Press.
- Rao, Pavithra. 2018. "Ending albino persecution in Africa: Governments, UN and human rights groups step up advocacy to enlighten communities." *UN Africa Renewal*. <https://www.un.org/africarenewal/magazine/december-2017-march-2018/ending-albino-persecution-africa>.

- Reimer-Kirkham, Sheryl, Barbara Astle, Ikponwosa Ero, Kristi Panchuk, and Duncan Dixon. 2019. "Albinism, spiritual and cultural practices, and implications for health, healthcare, and human rights: A scoping review." *Disability & Society* 34.5, 747–774.
- Rohrschneider, Robert, and Stephen Whitefield. 2009. "Understanding Cleavages in Party Systems: Issue Position and Issue Salience in 13 Post-Communist Democracies." *Comparative Political Studies* 42.2, 280–313.
- Schreier, Margrit. 2012. *Qualitative Content Analysis in Practice*. London: SAGE Publishing.
- Stoetzler, Marcel, and Nira Yuval-Davis. 2002. "Standpoint theory situated knowledge and the situated imagination." *Feminist Theory* 3.3, 37–49.
- Taylor, Julie, Caroline Bradbury-Jones, and Patricia Lund. 2019. "Witchcraft-related Abuse and Murder of Children with Albinism in Sub-Saharan Africa: A Conceptual Review." *Child Abuse Review* 28, 13–26.
- Terman, Rocjelle, and Erik Voeten. 2018. "The relational politics of shame: Evidence from the universal periodic review." *Review of International Organisations* 13, 1–23.
- True, Jacqui. 2010. "Mainstreaming Gender in Global Public Policy." *International Feminist Journal of Politics* 5.3, 368–396.
- Uganda Child Rights NGO Network. 2011. *Non-Governmental Organization (NGO) Report to the United Nations Universal Periodic Review*. Geneva: UN.
- Ugandan Human Rights Commission. 2016. *NHRI Submission for Uganda's Second UPR*. Kampala: UHRC.
- Under the Same Sun. 2013. *Poor Documentation of PWA Related Discrimination and Attacks in sub-Saharan Africa*, Surrey, B.C.: UTSS. <http://globaldisability.org/wp-content/uploads/2016/01/Poor-Documentation-re-PWA-in-Africa.pdf>.
- Under the Same Sun. 2017. *The Political and Civil Rights of People with Albinism in the Democratic Republic of Congo*. Surrey, B.C.: UTSS.
- Under the Same Sun. 2018. *People with Albinism and the Universal Periodic Review of Tanzania*. Surrey, B.C.: UTSS.
- United Nations. 2018. "Kenya makes progress in supporting people with albinism, but 'much remains to be done' says UN expert." *UN News*. 18 September. <https://news.un.org/en/story/2018/09/1019652>.
- United Nations. 2019. *Albinism worldwide: Note by the Secretary-General*. Geneva: UN A/74/190.
- United Nations Committee on the Elimination of Racial Discrimination. 2017. *Concluding observations on the fifth to seventh periodic reports of Kenya*. New York: UN CERD/C/KEN/CO/5-7.
- United Nations Committee on the Rights of the Child. 2015. *Committee on the Rights of the Child Concluding observations on the combined third to fifth periodic reports of the United Republic of Tanzania*. New York: UN CRC/C/TZA/CO/3-5.
- United Nations Country Team. 2016. *Country Team joint submission for the universal periodic review of the United Republic of Tanzania*. New York: UN.

- United Nations Human Rights Council. 2013. *Persons with Albinism*. UN A/HRC/24/57. www.ohchr.org/EN/HRBodies/HRC/RegularSessions/Session24/Documents/A_HRC_24_57_ENG.doc.
- United Nations Human Rights Council. 2021. *Human Rights Council Working Group, 3–14 May 2021, Compilation on Mozambique – Report of the Office of the United Nations High Commissioner for Human Rights** New York: UN A/HRC/WG.6/38/MOZ/2.
- United Nations Human Rights Council. 2021. *Resolution adopted by the Human Rights Council on 23 March 2021*. New York: UN A/HRC/RES/46/12.
- United Nations Independent Expert on the Enjoyment of Human Rights by Persons with Albinism. 2016. "Statement by the United Nations Independent Expert on the enjoyment of human rights by persons with albinism, Ms. Ikponwosa Ero, upon conclusion of her official visit to Mozambique – 21 August to 3 September 2016." New York: UN. <https://www.ohchr.org/EN/NewsEvents/Pages/DisplayNews.aspx?NewsID=20440&LangID=E>.
- United Nations Independent Expert on the Enjoyment of Human Rights by Persons with Albinism. 2019. *Visit to Kenya – Report of the Independent Expert on the enjoyment of human rights by persons with albinism*. New York: UN A/HRC/40/62/Add.3.
- United Nations Working Group. 2016. *Human Rights Council, Report of the Working Group on the Universal Periodic Review* United Republic of Tanzania, Addendum*. New York: UN A/HRC/33/12/Add.1.
- U.S. State Department. 2020. *Democratic Republic of the Congo: 2020 Human Rights Report*. Washington, DC: United States Department of State, Bureau of Democracy, Human Rights and Labor.
- UTTS (Under The Same Sun) Kenya. 2015. *Non-Governmental Organization (NGO) Report to the United Nations Universal Periodic Review*. Geneva: UN.
- UTTS (Under The Same Sun) Tanzania. 2016. *Non-Governmental Organization (NGO) Report to the United Nations Universal Periodic Review*. Geneva: UN.
- UTTS (Under The Same Sun) Uganda. 2016. *Non-Governmental Organization (NGO) Report to the United Nations Universal Periodic Review*. Geneva: UN.
- Vaughan, Elaine, and Anne O'Keeffe. 2015. "'Corpus Analysis' in *The International Encyclopedia of Language and Social Interaction*." London: Wiley, <https://doi.org/10.1002/9781118611463.wbielsii68>.
- Volken, Andrea. 2001. "Manifesto Research since 1979: From Reliability to Validity." In Michael Laver (ed.), *Estimating the Policy Positions of Political Actors*. London: Routledge, 78–94.
- Young Feminist Movement of Mozambique. 2021. *Non-Governmental Organization (NGO) Report to the United Nations Universal Periodic Review*. Geneva: UN.