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# Shifting Wrongs to Rights: Lessons in Human Rights from the Situation of Mothers Impacted by Albinism in Africa

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## Abstract

Debates about legitimizing human rights in Africa have centred on making universal human rights principles relevant to local social and cultural contexts. Localizing human rights norms requires seeing human rights in terms of relevance to specific situations rather than as the application of abstract principles. In this paper, scholars and advocates analyse the challenges in the practice of human rights, with a focus on mothers impacted by albinism, whether as mothers of children with albinism or as mothers with albinism themselves. Women and girls impacted by albinism are particularly vulnerable to human rights violations and reflect the unfulfilled promise of the United Nations principle to ‘Leave no one behind’. On account of intersecting factors—including denial of humanity; gendered stigma, discrimination and

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disenfranchisement; lack of access to the social determinants of health; and violence—mothers impacted by albinism are truly amongst those ‘furthest behind’. Drawing on the frameworks of vernacularization and culturalization, we conceptualize and contextualize human rights in relation to the unique experiences of mothers impacted by albinism in Tanzania, South Africa, and Ghana. Our analysis takes up four particularities that pose challenges to protecting the rights of mothers impacted by albinism: personhood as foundation for human rights; the communal nature of human rights; proportionality and human rights; and the intersectional nature of human rights. These particularities shed light on human rights practice for mothers impacted by albinism and carry implications for human rights practice more broadly.

**Keywords:** Africa; albinism; culturalization; gender; mothering; vernacularization

## 1. Introduction

Recent debates about legitimizing human rights in Africa have centred on how to make universal human rights principles relevant to local social and cultural contexts. Localizing human rights norms have been framed in terms of vernacularization and culturalization. This describes the process whereby global impulses intersect with indigenous ideas to produce new human rights norms and practices that are relevant to local situations, such that universal human rights norms become grounded in local communities. The notions of vernacularization and culturalization require seeing human rights in terms of their relevance to specific situations rather than as the application of abstract principles. Vernacularizing and culturizing human rights is, therefore, a constructive process that grounds and expands the scope of human rights in different cultural contexts (Merry 2006: 37; Lenzerini 2014). Rather than a cultural relativist repudiation of human rights universality, vernacularization connotes a deliberative process of investing universal rights with local meanings that can potentially strengthen human rights protection and contribute to the normative application of universal human rights (Ibhawoh 2018).

Drawing on the frameworks of vernacularization and culturalization, we conceptualize and contextualize human rights in relation to the unique experiences of persons with albinism and the challenges of human rights practice in Tanzania, South Africa, and other parts of Africa. Albinism is a relatively rare genetic condition that occurs worldwide but carries with it health risks and human rights urgencies in parts of Africa where the incidence of albinism is significantly higher, and the visibility of the condition is amplified (Hong et al. 2006; Kromberg and Manga 2018). In tropical climates, the lack of melanin that characterizes albinism results in a high risk of skin cancer in the absence of consistent application of sunscreen and protective clothing (such as long-sleeves and hats). Along with these health concerns, persons with albinism and their family members face attitudinal barriers that deny them access to work, education, and social inclusion.

As explained by Mswela (2018: 26), the skin colour of persons with albinism ‘makes it a condition that is loaded with symbolism and has led to several negative social constructions around this group of people, such as the association of fair skin colour with harmful myths, false notions, and curses’. Persons with albinism are often constructed as Other due to deeply rooted, spiritualized beliefs about the condition that construct them as sub-human or super-human (Imafidon 2017). Moreover, many live in constant vigilance on account of violent attacks, dismemberment, and murders of persons with albinism (UN Human Rights

Council 2017a). A spike in attacks and violence starting in 2007 resulted in the appointment by the UN Human Rights Council of an Independent Expert on the enjoyment of human rights by persons with albinism in 2015, with the first mandate holder being Ikponwosa Ero, herself a person with albinism and a lawyer.

The creation of the mandate of a UN Independent Expert on Albinism shows a shift at the international level towards a human rights approach to albinism. Ero's Reports to the UN and other work in fulfilling the mandate have been instrumental to moving the cause forward and ensuring that international and national attention continues to spotlight concerns of persons with albinism and their families. It has also articulated the framework of human rights instruments and standards relevant to the cause of persons with albinism. These span fundamental rights to life, security of person, freedom from torture and other cruel, inhuman, or degrading treatment or punishment, and the right to the highest attainable standard of health as well as particular standards relating to the rights of persons with disabilities, the rights of women; children; protection from harmful practice and racial discrimination (see Table 1).

However, the conditions of persons with albinism reflect the unfulfilled promise of the UN principle to 'Leave no one behind' (LNOB) (UN 2021). LNOB is the central, transformative promise of the UN 2030 Agenda for Sustainable Development and its Sustainable Development Goals (SDGs) (UN General Assembly 2015; UN 2021). It represents a commitment of the international community to combat discrimination and exclusion, and reduce the inequalities and vulnerabilities that leave people behind and undermine the potential of individuals and communities. LNOB not only entails reaching the poorest of the poor but also requires combating discrimination and rising inequalities within and amongst countries, and their root causes (UN 2021). Women and girls impacted by albinism are particularly vulnerable to human rights violations (Reimer-Kirkham et al. 2022; UN Human Rights Council 2019a). On account of a constellation of intersecting factors—including denial of humanity; gendered stigma, discrimination and disenfranchisement; lack of access to the social determinants of health; and violence—the mothers impacted by albinism are truly amongst those 'furthest behind' (UN General Assembly 2018: para. 21).

In this paper, scholars and advocates from the Global South and Global North analyse the challenges in the practice of human rights, with a focus on mothers impacted by albinism. We draw on a four-year interdisciplinary project, *'Mothering, albinism, and human rights in Africa: Mapping patterns of resilience at the juncture of gender, colourism, and religion'* (SSHRC #435-2019-1120). Employing ethnographic methods, Phase I of the project was completed in 2019 in Tanzania, where we conducted a focused critical ethnography to gain first-hand understanding of the lived experiences of mothers impacted by albinism, and the contextual factors shaping these experiences. We conducted interviews, focus groups, and participant observation alongside cultural liaison who spoke with participants in the shared language of Kiswahili. Participants included mothers impacted by albinism and key stakeholders such as teachers, social workers, nurses, faith leaders, journalists, policymakers, and Civil Society (CSO) advocates ( $n = 62$ , 26 mothers and 36 key stakeholders). The research processes included an initial six-week period of fieldwork in Dar es Salaam and Mwanza, Tanzania, when we worked closely with CSO partners who facilitated access, recruitment, and data collection. A follow-up three-week fieldwork period allowed us to complete data collection and validate our interpretations. Phase II is currently underway in South Africa, with virtual data collection methods due to the global pandemic ( $n = 13$ ). Phase III in Ghana is pending. A close reading of the narratives of mothers

**Table 1. Relevant human rights instruments for the case of albinism**

International instruments	Regional instruments	Albinism-specific instruments
Universal Declaration of Human Rights ( <a href="#">UN General Assembly 1948</a> )	African Charter on Human and People’s Rights ( <a href="#">ACHPR 1986</a> )	Pan-African Parliament, Resolution on Concrete Measures for the Promotion and Protection of the Rights of Persons with Albinism in Africa ( <a href="#">Pan-African Parliament 2019</a> )
International Covenant on Economic, Social, and Cultural Rights (ICESCR) ( <a href="#">UN General Assembly 1976a</a> )	African Committee of Experts on the Rights and Welfare of the Child ( <a href="#">ACERWC 1999</a> )	Regional Action Plan on Albinism (2017-2021) UN Human Rights Council ( <a href="#">UN Human Rights Council 2017a</a> )
Convention on the Elimination of Discrimination Against Women (CEDAW) <sup>1</sup> ( <a href="#">UN General Assembly 1979</a> )	Protocol to the African Charter on the Rights of Women in Africa [the Maputo Protocol] ( <a href="#">African Union 2005</a> )	
Convention on the Rights of Persons with Disabilities (CRPD) <sup>2</sup> (UN 2006)	263 Resolution on the Prevention of Attacks and Discrimination Against Persons with Albinism ( <a href="#">African Commission on Human and People’s Rights 2013</a> )	
International Covenant on Civil and Political Rights (ICCPR) ( <a href="#">UN General Assembly 1976b</a> )	Article 5 of the Protocol to the African Charter on Human And Peoples’ Rights on the Rights of Persons With Disabilities in Africa [contains a non-discrimination clause.] Article 5 (2) (c) ( <a href="#">African Union 2018</a> )	
International Convention on the Elimination of All Forms of Racial Discrimination (CERD) ( <a href="#">UN General Assembly 1969</a> )		

(continued)

**Table 1.** (continued)

International instruments	Regional instruments	Albinism-specific instruments
Convention against Torture and Other Cruel, Inhuman, or Degrading Treatment or Punishment ( <a href="#">UN General Assembly 1987</a> )		
Declaration on the Right to Development ( <a href="#">UN General Assembly 1986</a> )		
Declaration on the Right and Responsibility of Individuals, Groups, and Organs of Society to Promote and Protect Universally Recognized Human Rights and Fundamental Freedoms ( <a href="#">UN General Assembly 1998</a> )		
International standards on freedom of religion or belief ( <a href="#">UN OHCHR 2021</a> )		

<sup>1</sup>CEDAW makes specific reference to women with albinism within its mandate (See CEDAW/C/BDI/CO/5-6, [CEDAW/C/TZA/CO/7-8](#), [CEDAW/C/SWZ/CO/1-2](#) and [CEDAW/C/MWI/CO/7](#)).

<sup>2</sup>CRPD makes specific reference to women with albinism within its mandate (See CEDAW/C/BDI/CO/5-6, [CEDAW/C/TZA/CO/7-8](#); See [CRPD/C/KEN/CO/1](#)).

impacted by albinism reveals three interwoven themes: their sense of societal obligations toward them (the world as it ought to be); their obligations to the community (their contributions to the world); and their efforts to bridge between these sets of obligation, as they reframe traditional communitarian values to create their own space for rights-entitlements, social inclusion and empowerment through peer-support mothers' groups, thereby converting wrongs to rights.

As will become evident in what follows, the denial of human rights faced by mothers impacted by albinism is not primarily because of a lack of legal frameworks, but rather due to the practice of human rights and the implementation (or lack thereof) of the socio-cultural frameworks of their everyday lives. The case of albinism involves several particularities that can pose challenges to the implementation of human rights. Our analysis takes up four of these particularities: (1) personhood as the foundation for human rights; (2) the communal nature of human rights; (3) proportionality and human rights; and (4) the intersectional nature of human rights. These particularities shed light on human rights practice for mothers impacted by albinism, and carry implications for human rights practice more broadly.

## 2. The human in human rights: personhood as a foundation for human rights

A taken-for-granted assumption in the conceptualization of human rights is that the understanding of what constitutes a human and what it means to be human is universally shared with minimal contestations. This taken-for-granted assumption of being human emphasizes the biological and anatomical foundational features such as being a bipedal *homo sapiens* (the scientific conception of a human person). But it largely ignores the normative and social constructions and narratives of humanness and personhood, constructions and narratives that play vital roles in the enjoyment and denial of rights in particular and localized horizons of existence. The subaltern and superaltern linguistic forms of the human such as suprahuman,<sup>1</sup> subhuman, less-than-human, inhuman, and nonhuman are expressions of real and lived experiences of the normative understanding of the human that saturates human history and societies.

Social identities such as those pertaining to race, gender, disability, and queerness often find their departure points from the normative and social constructions of the human. For example, slavery in many societies was sustained for centuries through the dehumanization of those enslaved. Similarly, characterizing vulnerable groups as non-human has provided justification for committing genocide and other atrocities against them, as was the case of the Holocaust, where Jews were characterized as sub-human, and in the Rwandan genocide, where Tutsis were also characterized as less than human (Smith 2011). Hence, for any discourse of the challenges to implementing human rights in specific contexts to be fruitful, it should pay attention to the constructions of the 'human' within such contexts. As put by Ibhawoh (2018: 19), 'human rights are first and foremost representations of ideas about

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1 We use the concept of suprahuman rather than superhuman because the prevalent attitude towards persons with albinism in the context of this study is not that they have attributes beyond what is possible for a human being (superhuman) but that they embody powers that are above and beyond that of a normal human, hence the supernatural powers attributed to their body parts which make them vulnerable to killings and mutilations.

human dignity and human worth'. This is crucial in understanding the lived experiences of persons with albinism in African societies.

A central challenge faced by persons with albinism in various parts of Africa is that often, their very humanity remains in question, and as a result, utilizing constitutional human rights frameworks to the benefit of persons with albinism is hindered. International human rights are centred on an assumption of universal humanity and dignity. These rights are unique and different from earlier articulations of the 'rights of man' because they are not contingent on the social status of identity. The idea of universal humanity and human dignity frames human rights discourse by making it a distinctive kind of discourse that articulates the most urgent claims of the human person in social life (Gilbert 2019: 1). Noting that disregard and contempt for human rights have resulted in barbarous acts which have outraged the conscience of 'humankind', the Universal Declaration of Human Rights (UDHR) affirms that the 'inherent dignity and of the equal and inalienable rights of all members of the human family is the foundation of freedom, justice and peace in the world' (UN General Assembly 1948). Universal human rights are therefore premised on the essential dignity and worth of the human person and the equality of all humans. Yet, in contravention of this premise, persons with albinism have been constructed as being outside of 'the human'. The complication here is not simply that persons with albinism are constructed as subhuman (as we have seen with slavery and genocidal doctrines) but that they are also sometimes constructed as suprahuman. Both constructions, we argue, present unique hurdles for using a standard human rights framework in protecting the rights of persons with albinism. We suggest that vernacularized or culturalized human rights frameworks and discourses are better suited for protecting the rights of persons with albinism.

As a fundamental expression of their entitlement to human rights—what ought to be—the mothers included in our Tanzanian fieldwork recognized and emphasized the need for their communities to see them and their children as human beings. In the words of Goma (pseudonym), a mother with albinism in a rural context in the Tanzanian Lake Zone, '*People need to understand that albinism is in [all communities] and that persons with albinism are human beings like any other human being. So, stop discriminating against us on the basis that we are not human*'. Goma articulates here a moral obligation to non-discrimination, based on the humanness of persons with albinism, that they are within the human family that all deserve to be free from discrimination.

Similarly, in a focus group of mothers impacted by albinism in the same region, Editha, a mother with albinism, described how people in her community spoke about her, '*that's not a human being, that's a pig*'. Names used for people with albinism include goat, pig, ghost, abominable creature, financial deal, among others (Brocco 2015; UTSS n.d.; UN General Assembly 2016). Similarly, families of children with albinism name their children 'problem' (*Shida*) or 'global challenge' (*Matatizo dunia*), denoting both the view of their children and forecasting their personal social status due to the birth of the child (personal communication, P. Senkoro 21 September 2021). Name-calling is not unique to the situation of persons with albinism; what is unique is the deep ontological denial of personhood that leads to human rights violations, such as discrimination, segregation, and violence. Editha's in-laws told her, '*you've brought a bad seed in our family. We do not want that woman*'. She went on to say that her husband had also been segregated because of her. With the denial of Editha's humanity came judgement, discrimination, and exclusion (including discrimination based on association, as experienced by her husband).

The non-humanization (not strictly de-humanization) of persons with albinism is significant because it questions a fundamental premise of universal human rights doctrine. If human rights are rights that pertain to people by virtue of their humanity, how do we protect the rights of those who, in certain social and cultural contexts, are considered non-human, suprahuman, or sub-human? This is the central challenge posed by human rights practices in relation to persons with albinism. Any successful application of universal human rights in the African context must begin with the starting point of personhood—to find locally embedded (vernacular) affirmations that persons with albinism are fully human. A first step in protecting the human rights of persons whose very humanity is denied or questioned, is to affirm their humanness in the specific socio-cultural context of their lived experience. The priority is to identify local practices that can potentially destabilize those social and cultural foundations that support de-humanizing characterizations, thus opening space for vernacular human rights.

### 3. Human rights as social inclusion: reclaiming membership in community

A second particularity regarding the application of human rights relates to the communal readings of human rights. In contextualizing human rights to Africa, it is generally held that communitarian readings should take precedence over individualistic interpretations. According to [Ibhawoh \(2018: 37\)](#), the notion of an African concept of human rights is linked to longstanding philosophical debates about African conceptions of human nature. At the heart of this debate is the claim that communal African conceptions of human nature stand in contrast to Western liberal conceptions, which foreground humans as autonomous individuals defined by their intrinsic worth. In the African conception of human nature, individual identity is grounded in social interaction and community life.

Yet, for many persons with albinism in Africa, even in a communitarian context, a paradoxical exclusion results from their physical and ontological otherness. The cosmology of interrelated entities (human beings, animals, plants, minerals, events, natural and supernatural) results in an interconnected, interlocked African community that may practice exclusion of beings or entities to ‘protect the socially approved web of relationships from anything that may threaten its harmony and equilibrium’ ([Imafidon 2017: 166](#)). Because of this worldview, citizens may carry a strong conviction that ‘persons with albinism deserve the ill-treatment done to them because they are not an “Other” towards whom one has some form of responsibility, but a degraded nonhuman other who is nothing but a threat to the established community of beings’ ([Imafidon 2017: 168](#)). Appealing to traditional African notions of human rights as communal can thus become problematic because they fly in the face of the fact that in some situations, such as the experiences of people with albinism, this definition of communal is (paradoxically) restrictive and exclusive. In the case of persons with albinism, because they are not considered human in such contexts, they are not part of the community to begin with. For this reason, [Imafidon \(2017: 170\)](#) argues for a connection of a local ethical stance to a broader ‘moral point of view that concerns what is equally good for all’.

We return to the narratives of mothers impacted by albinism and other key stakeholders for clues about how this paradox is worked out in their everyday lives; in how they conceptualize human rights language, and how local knowledge and practices create space for the enjoyment of human rights by persons with albinism. Although most mothers and local



advocates in our study did not draw on legal frameworks per se, they carried an awareness of imperatives in forms of what ‘ought’ and ‘ought not’ to be done and thus intuitively communicated breaches of certain human rights-related norms, and what barriers and opportunities to those norms existed.

As illustrated in Goma’s and Editha’s assertions above, and as a fundamental expression of their entitlement to human rights—what ought to be—the mothers included in our Tanzanian fieldwork recognized the need for their communities to see them and their children as human beings. In this way, mothers hinted at their entitlement to human rights, with a sense of what was morally right and the duties of individuals within their community vis-à-vis those rights. They did so in a manner akin to the duties of individuals towards the family and toward the community as enshrined in the African Charter on Human and People’s Rights (1986) which outlines the duty of individuals to ‘preserve the harmonious development of the family and to work for the cohesion and respect of the family’ (Article 29(1): 8). The Charter also specifies the duty of the individual to preserve and strengthen positive African cultural values in their relations with other members of the society (Article 29(7): 9).

Goma’s words cut to the heart of the matter: ‘*Stop discriminating against us on the basis that we are not human*’. The use of the word ‘discrimination’ here might be interpreted as an example of law, in this case, human rights, casting a long shadow, shaping the articulation of the local in a broader discourse of rights. The notion of the shadow of the law has been described by Fokas (2015: 74) as the place ‘where we find evidence of the fact that judicially articulated legal norms take a life of their own when deployed in social actions; and it is here that we can detect how the messages of the courts may be amplified, cancelled, or transformed by the presence of indigenous norms and controls, in ways that lie well beyond anticipation of the courts or the scholars studying them’. The point of the shadow of the law is to articulate how law circulates outside of law and the courts. Human rights are part of law’s shadow, circulating globally and enacted and interpreted locally. Goma calls for a reconceptualization that draws on a fundamental understanding of equality and inclusion.

Human rights are, at their essence, about social inclusion. The UDHR (1948: 1) affirms the inherent dignity and ‘equal and inalienable rights of all members of the human family’. The exclusions experienced by mothers impacted by albinism from the ‘human family’ of their local communities have become sites of resistance and reformulation of a much-valued sense of community and social inclusion through peer support. Our fieldwork with peer-support groups (referred to as ‘mamas’ groups’) of mothers impacted by albinism (whether as mothers themselves with albinism, or those having given birth to a child with albinism) has revealed local solutions to human rights violations. In addition to shared micro-economic activities to offset poverty, the mamas’ groups provided social support to counter attitudinal barriers, particularly those based on functionalism; support against gender-based violence; and protection from familial abandonment, community banishment, attacks, and other harmful practice. Fundamentally, women’s responses in taking up peer-support groups are human rights responses to bring about structural and substantive change.

Consider the example of Inaya, a mother of two children with albinism (18 and 12 years old) who is separated from her partner. Recalling her worries related to the safety and security of her children, she stated, ‘*my main worry is that to protect a human being is a real challenge. ...I quit my job to take care of my children*’. While her ex-husband did provide money for food, Inaya needed more income for rent, school fees, and other expenses.

Through a connection with a CSO, Inaya met other mothers impacted by albinism and was part of forming a women's group in Dar es Salaam. She hosts the group in her home and has developed leadership skills in this role, mentored by staff from the CSO. Together these women make various products to sell in artisan fairs and in storefronts. This income is generated and shared collectively in an environment where their children are welcome and safe.

Inaya has a strong sense of what 'ought' to be extended to her with respect to humanness, human dignity, and social inclusion. The implicit human rights narrative here is that Inaya and her children with albinism are excluded from her community, resulting in deprivation. Along with other mothers in the peer group, they leverage traditional communal values around social inclusion through a construction of their own community where they belong and take identity. Extending their (implicit) expression of human rights, mothers directly linked cosmological beliefs about the non-humanness of persons with albinism to social exclusion from their communities, and through their peer-support activities created new communities of empowerment. In this way, they mobilized deeply rooted beliefs about community (traditional knowledge) to create a parallel but more inclusive community to not only survive and thrive but also to challenge assumptions about non-humanness, and in this way, lay claim to their basic human rights. To return to our initial discussion, these mothers have crafted a vernacular strategy that works toward displacing the exclusion of persons with albinism. By integrating the spirit of human rights into everyday understandings of fairness and justice the 'mamas' are shifting the cultural and social foundation that positions persons with albinism as 'less than' or outside of the conceptualization of the human.

Other community actors deployed more explicit human rights discourse, coupled with traditional local knowledge about the human dignity of persons with albinism and hence their inclusion in society, revealing how multi-vector responses accumulate to bring about social change. Many albinism-related CSOs work to improve the well-being of persons with albinism, often through education, health services, and social support. These organizations provide another level of the work that needs to be done to shift or destabilize the foundation that holds that persons with albinism are not part of the human family. For example, CSOs like Under the Same Sun (UTSS) and Standing Voice (SV) focus their efforts on disrupting stereotypes and working towards bridging the 'us' and 'them' through community education. Whether giving seminars or staging dramas that illustrate the challenges that persons with albinism face in their day-to-day lives, the goal begins with getting the audience to experience life in 'their shoes'. This invitation to empathy engages the audience to consider the fact that persons with albinism deserve equal access to human rights, including non-discrimination. Moreover, by their links to regional and global albinism advocacy networks, the local efforts of CSOs contributed to the international human rights agenda once the UN Independent Expert on albinism mobilized a human rights movement.

Adding additional sites of change, CSOs reached out to well-placed community ambassadors in the social institutions of healthcare, education, and religion to facilitate community understanding of the true nature of albinism and debunk existing myths about the condition. Nurses interviewed at a hospital in Mwanza described how representatives from a CSO with albinism themselves had delivered albinism education to hospital leadership. Sakina, a head nurse on a labour and delivery ward, recalled how '*there was a lot of emphasis on labour and if a mother delivers a child with albinism. . .to emphasize to [staff] on the issue of acceptance and treating everybody alike*'. A similar organizational shift was set in

motion at a local boarding school. A teacher and counsellor for students with albinism at a boarding school, Maneno, remembers how teachers assumed children with albinism had low IQs and were generally going to be poor students. As the headteacher for these students, Maneno highlighted the shift in thinking across the entire school after a CSO presented their 'Understanding Albinism' training (staff and students). Gradually staff became more open and accepting of the students. Maneno continued as the community ambassador for the well-being of children with albinism at this school. These interventions draw on human rights language, but it is a uniquely vernacularized human rights language that aims to shift exclusionary cultural and social attitudes.

The social institution of religion offered yet another site for human rights advocacy. Joseph, a Christian pastor (Tanzania Assemblies of God) in Mwanza, described the transformation in his congregation following an 'Understanding Albinism' seminar through a CSO at his church. He described how after *'exposure time. . . church members start touching [people with albinism], they get used to them, staying with them, eating [together]. . . our kids are [growing up without] that kind of separation or that segregation. . . they know that these are normal people'*. Joseph's congregation has gone beyond acts of charity and has instead built relationships with people in their community affected by albinism. Recalling a couple in the church who delivered a baby with albinism, Joseph said that the mother was *'worried about coming [to church] but then was encouraged, she came, and the congregation loves her child. They are very much accepted'*. This example speaks to the widespread existence of discrimination against persons with albinism, also residing within faith communities. The pastor recognized this problem and once he was given the tools by the CSO to dismantle assumptions about persons with albinism, he became an effective community ambassador. His successful actions stand as illustration of intergroup contact theory (Pettigrew, Tropp, Wagner & Christ 2011), whereby contact between people who are different can change attitudes.

Notably, CSOs conduct most of the community education and advocacy work within Tanzania. Yet, the government as primary duty bearer of the right of persons with albinism has not mainstreamed such education or taken on the responsibility of making provision on a country-wide level. Relatedly, in each of these social institutions, the challenge of scaling up is a factor, in part because of the lack of coordinated, national networks or systems. Yet, local ambassadors can contribute to the possibility of embedding sustained attitudinal change and spaces of acceptance by drawing on both human rights principles and inclusive re-interpretations of local beliefs about community. Opportunities for connection with persons with albinism, whether a seminar presenter or a child with albinism at a church, have been powerful vehicles for changing attitudes.

#### 4. The problem of numbers: proportionality and human rights

A challenge to direct government intervention—in terms of specific measures grounded in human rights—in the situation of persons impacted by albinism is one of numbers. This is the third unique challenge in the application of human rights for persons with albinism. The challenge encompasses the relative rarity of albinism in the general population, and the absence of systematic data about the occurrence of abuse and violent attacks. Combined, these allow governments to justify inaction, particularly in relation to the implementation of response strategies rooted in human rights. This problematic raises the question of whether attacks against persons with albinism are isolated incidents of violence or systemic

patterns of human rights violations. Being a relatively rare condition, the number of reported cases of attacks and discrimination against persons with albinism could be viewed as minimal compared to other violations against other people groups. Take, for instance, the reported death toll of nearly one million persons in the four-month long genocide in Rwanda, versus the ‘small-scale humanitarian crisis’ ([International Federation of Red Cross and Red Crescent Societies 2009](#): 6) of persons with albinism with about 10 reported cases of attacks including murders against persons with albinism in the same time frame.<sup>2</sup> Does the latter warrant the full engine of the State? Does it warrant a United Nations mandate?

The problem of numbers and the correlating issue of administrative expediency should be addressed with pointed advocacy relying first on the important issue of relative proportionality taken in its ordinary sense. In the case of persons with albinism, the element of relative proportionality underscores the severity of the human rights issues at stake. These include the facts that persons with albinism are targets of hate crimes threatening their fundamental rights to life; that their vulnerability to these crimes is aggravated by existing notions of albinism as mystical and persons with the condition as non-human or sub-human Other; their hyper-visibility due to their complexion in most African communities, and a verified pattern of perpetrator-family members. Moreover, due to their relatively few numbers, one murder could effectively be the killing of a third of the population of persons with albinism in one village, leading the surviving two to extreme vulnerability and a life of fear that abnormally erodes their enjoyment of the right to life.

The threat of violence has profound impacts on the lives of mothers living with albinism, extending far beyond the actual number of attacks. Consider this account from our Tanzanian fieldwork: Amana recounted how a man attempted to lure her daughter into his car as she was steps away from her school entrance. This attempt was interrupted by a watchful teacher who intervened by calling her daughter’s name and thus scaring off the perpetrator. This experience led to Amana feeling that unless she was available to walk her daughter to and from school, she could not guarantee her safety. Because of the need for constant vigilance, Amana struggled to earn a livelihood; like other women in this mamas’ groups, she stated, *‘I can’t even manage to look for a job because I have to be there somehow for the child to take her to school and bring her back. We struggle a day at a time...’*

An example from Nomandia, a woman in the Gauteng Province of South Africa, highlights the effect when albinism is not mainstreamed enough within government and social services to make the benefits available well known. Nomandia recounts her experience attempting to register her baby with albinism for the disability grant she is entitled to: *‘I remember when I went to SASA to register my baby... They refused to give me [the disability] grant saying that... she doesn’t have a disability. Her eyes are good, so they don’t think that I should get that... I think that one was not fair to me because some other women, they do get that grant, and some they get it when they say disability’*.

In both contexts, because of continued misunderstanding around albinism as a condition, the burden falls on the mother, child, and broader family, both in terms of self-advocacy as well as resulting socio-economic burden. In Tanzania, Amana’s story illustrates how very present safety and security concerns impact employability, where employers lack an appreciation for such threats. Nomandia’s South African experience highlights the tension where government support does exist, but those appointed to ensure such supports are

2 Number of cases reported to the Independent Expert (IE) between November 2020 and February 2021.

dispersed have the power to pick and choose recipients based on flimsy guidelines or personal understandings of a condition, particularly albinism which remains largely misunderstood.

Several countries, including Kenya and South Africa, have enacted laws, and created government departments dealing specifically with groups exposed to vulnerability. This is a best practice as it does not leave the burden of establishing administrative importance to a group that is already marginalized. Both countries have responded to the situation of persons with albinism in their countries by taking concrete steps to establish policies and national action plans to affirm, protect and fulfil the human rights of persons with albinism (UN Human Rights Council 2019b; 2020). Tanzania, on the other hand, does not take this approach to the situation of persons with albinism. The reasons seem to tether around administrative fairness vis-à-vis other groups with disabilities who justifiably feel left behind. While Tanzania took the approach of Kenya and South Africa when attacks against persons with albinism were at their height in the country, that approach seems to have been limited to the apparent emergency and not extended to a broader protection measure like a national action plan on albinism or the incorporation of specific measures for the protection of persons with albinism into relevant national portfolios (UN Human Rights Council 2017b). Accordingly, as at 2022, Tanzania had not yet adopted a national action plan, even though a draft created by civil society exists, and even though the country has been the historical epicentre of human rights violations against persons with albinism (UN Human Rights Council 2017b). This has left persons with albinism vulnerable to continued attacks and other violations.

Also related to the matter of numbers is the balance of global representation. Ero argues for the necessity of acknowledging the impact of positions of power where the prevalence rate of albinism is highest in the Global South versus prevalence rates that are generally low in the Global North/West. This poses a serious challenge to human rights advocacy for albinism that is both organically home-grown and effective on the international stage, one that links the local to the universal. However, the reality is that human rights scholarship is still largely an 'elitist' area of study where the critical mass is in the West and must be accessed for a movement on albinism to gain traction in the international human rights community. This is indeed how the situation of persons with albinism was placed on the international human rights agenda.<sup>3</sup> While effective, it runs the risk of a blanket application of human rights to the situation with little consideration for local social and cultural contexts. Contextualization is necessary to both incorporate human rights into the milieu and social framework of its beneficiaries, as well as to locate local challenges to its implementation.

## 5. Aggregating human rights violations: the intersectional nature of human rights

The final challenge of albinism relates to the convergence of sources of discrimination experienced by mothers impacted by albinism. Ero has documented the intersecting and multiple forms of discrimination experienced by persons with albinism based on disability, colour, and gender (UN Human Rights Council 2019a; Ero et al, in press), often exacerbated by a lack of access to the social determinants of health (what one mother referred to

3 Primarily through advocacy at the UN by CSOs based in the Global North. In particular, Under the Same Sun.

as ‘*basically, how are we going to live*’). Multiple or intersecting discrimination is a situation where several grounds for discrimination operate and interact with one another at the same time in such a way that they are inseparable and compounding (UN General Assembly 2017). This notion of multiple and intersecting discrimination affecting persons with albinism is firmly rooted in international and regional human rights jurisprudence (UN Human Rights Council 2013).

A wide variety of human rights mechanisms both at the UN and at the AU have applied their non-discrimination provisions to the situation of persons with albinism (Reimer-Kirkham et al. 2022). Table 1 displays the range of international, regional, and albinism-specific human rights instruments that the UN Independent Expert on Albinism has drawn upon in their mandate reports. These include the Committees of the International Covenant on Civil and Political Rights, the International Covenant on Economic, Social and Cultural Rights, the Convention on the Elimination of All Forms of Discrimination Against Women, the Convention on the Rights of Persons with Disabilities, as well as the African Commission on Human and Peoples’ Rights, the African Committee of Experts on the Rights and Welfare of the Child, and the newly minted Protocol to the African Charter on the Rights of Persons with Disabilities (see Table 1). The African Charter on the Rights of Persons with Disabilities specifically mentions persons with albinism in its preamble and contains an expanded section on harmful practices in response to the situation of persons with albinism, which was particularly heightened during the drafting and consultation processes of the Disability Protocol. Especially relevant to the case of persons with albinism, the African Charter on Human and People’s Rights (ACHPR 1986) places emphasis on families and society, and the duties an individual has toward preserving harmonious relations in the family and in the community where that individual belongs.

Returning to the experience of Goma, who we met above (a mother with albinism), we see powerful intersecting forms of discrimination. She described her experience seeking prenatal care at her local clinic. She recalled a nurse demanding to know, ‘*Why are you coming here? This is a pregnant mother’s ward.*’ When she told the nurse she was indeed pregnant, the reaction was shock and disbelief: ‘*Are you sure you are pregnant? You?*’ This disbelief highlights the kind of questioning women with albinism face, calling into question the biological ability to conceive as a woman, along with places such as a prenatal clinic where they were not seen to belong. Goma was stigmatized and ostracized by those who were charged with caregiving. The nurses at the clinic refused to touch her without gloves. As with Editha, Goma’s narrative illustrates the intersectional (colour, disability, and gender) dimensions of discrimination.

Discrimination based on colour and disability co-exists with gender inequality and deprivation, resulting in multiple and intersecting human rights violations where women impacted by albinism bear a disproportionate burden of such violations. As a cross-cutting principle, equality and non-discrimination ‘is present in all major human rights treaties’ (UN OHCHR 2020: para. 8) and, as such, provides much of the basis for approaching the concerns of those with albinism. While disability rights offer a powerful protective for human rights interventions for persons with albinism, within some African contexts, the general public often does not first associate or identify persons with albinism as persons with disabilities (personal communication, P. Senkoro 31 March 2021). Instead, colour is the primary identifier and often the main source of discrimination due to the various beliefs attached to it (e.g., persons with albinism as supernatural beings, ghosts, that a white flesh of an otherwise black African is what brings wealth). Ironically, the colouring in persons with

albinism results from an impairment in melanin synthesis, meaning the colour is also a source of disability and racial discrimination. This contextual specificity points to the value of the aggregation of human rights, recognizing overlapping experiences, particularly of colour, disability, and gender. It also underscores the need for creative and contextually grounded approaches to human rights advocacy. In Tanzania, discrimination based on disability, colour, and gender represent key human rights themes in international and national human rights laws under which Tanzania as a Member State of the United Nations, has specific obligations. A listing of relevant human rights instruments that Tanzania<sup>4</sup> (as are the other UN Member States) is obligated to, serves to re-iterate the premise of this paper; namely, that it is not a lack of legal frameworks that has resulted in the human rights violations against persons with albinism, but rather it is due to gaps in the practice of human rights.

## 6. Discussion

Our analysis makes visible the dialectics between universal and local interpretations, between international and regional human rights instruments, and between formal and informal human rights practices.

### 6.1 Universal and local interpretations

In our research, we find that across Africa, persons with albinism are drawing on global human rights discourses while concurrently working within traditional and local systems to change cultural and customary attitudes. Avoiding the privileging of dominant (i.e., Western, conventional) understandings and approaches to human rights above others is crucial, as is allowing for dissenting and critical voices within widely accepted interpretations of ‘African’ or ‘communal’ conceptions of human rights. As an interdisciplinary, multinational research team, we argue for an approach that acknowledges the hegemony of Western *episteme*<sup>5</sup> and therefore seek to know the origin of voices and what impulses might be animating their position. Related to traditional African beliefs about the essential human nature of persons with albinism are the spiritualized cosmologies characteristic of many African contexts, whereby it is understood that a vital force or common energy of ‘cosmic origin permeates and lives within all that is—human beings, animals, plants, minerals, and objects, as well as events’ (Imafidon 2018: 31).

The interrelatedness that emanates from such metaphysics holds consequences for human rights scholarship in the African context. Rooted in rationalism, proceduralism, and secularism—the ideologies of Western liberalism (Mutua 1995, 2001)—conventional

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4 Tanzania has ratified the Covenant on Civil and Political Rights, the International Covenant on Economic, Social and Cultural Rights, the Convention on the Rights of Persons with Disabilities, the International Convention on the Elimination of All Forms of Racial Discrimination, the Convention on the Rights of the Child, and the Convention on the Elimination of All Forms of Discrimination against Women. At the regional level, Tanzania has ratified the African Charter on Human and Peoples’ Rights, the Protocol to the African Charter on the Rights of Women, and the African Charter on the Rights and Welfare of the Child.

5 Here we refer to critiques of universal human rights by Hopgood (2013), Barreto (2014), Mutua (2016) and Samson (2020), who argue that human rights compromise a hegemonic liberalism and globalized superstructure of norms and institutions to sustain it.

human rights instruments that do not account for spiritualized cosmologies and Indigenous religions risk a reduction in relevance, legitimacy, and impact. A philosophical framework such as that presented by Imafidon points to potential sites of human rights vernacularization—connecting African traditions about being, knowledge, and the good to human rights for persons with albinism, especially when the essence of being human is the capacity to be in communal relationships (Metz 2014). Human rights approaches can then be universalist and formalistic but also contextual and vernacularized. As Sally Merry (2006: 1) explains, ‘in order for human rights ideas to be effective, they need to be translated into local terms and situated within local contexts of power and meaning. They need, in other words, to be remade in the vernacular and the vernacular supported with a legal framework’.

## 6.2 International and regional human rights instruments

Rights advocacy frameworks are made more impactful when they build on locally rooted demands for meaningful freedoms within particular cultures. They become embedded in everyday social practices, shaping the rules people carry in their individual and communal hearts. Yet, there is a great distance between global sites where these ideas are formulated and the specific situations in which they are deployed (Merry 2006: 538). For this reason, the movement toward the Africa-focused strategies through the Regional Action Plan (2017–2021) (UN Human Rights Council 2017a) and its extension, the Plan of Action on Albinism (2021–2031), which emerge from the African Regional Human Rights Framework, carry hope for the sustainable enjoyment of human rights by persons with albinism and their family members and for a way to localize human rights interpretations. Both international and regional human rights frameworks are required.

## 6.3 Formal and informal human rights practices

Along with the dialectics of universal and local, international and regional, this research also demonstrates the complementarity of formal and informal human rights practice. We seek to prioritize local voices and experiences in thinking about the intersection of human rights and the protection of persons with albinism, mapping not only harms to persons with albinism but also working on the ground to achieve deep equality (Beaman 2017). Negotiating and navigating difference in positive ways by the multiple social actors we have identified in this paper—‘the mamas’, the CSOs, nurses, pastors, community leaders—offers on-the-ground solutions and responses to discrimination against persons with albinism. By identifying their actions and telling the stories of the ways in which they recraft social relations to include and support persons with albinism, everyday equality is furthered, as is the building of vernacular human rights. While these changes may seem painfully slow, they are stabilized from the ground up, which facilitates deep roots for social change. In the case of mothers impacted by albinism in Tanzania, we have found that they generally lack knowledge of relevant legal frameworks and conversely that universal human rights frameworks tend not to encompass the complexities of spiritualized, communal African contexts. Yet, with closer inquiry, we see that this gap is not as wide as might be anticipated. The mothers shared a sense of ‘ought’ as a pathway to end discrimination and bring about social inclusion. Significantly, they are drawing on local cultures of communal solidarity to support each other, build alliances and challenge exclusionary social practices. They stepped up as human rights defenders for their children and other persons with albinism. CSOs and other community actors served as intermediaries between



understandings of albinism and human rights. In this spirit, legal wrongs were converted to human rights.

## 7. Conclusion

Facing an assemblage of intersecting forces, mothers impacted by albinism are particularly vulnerable to human rights violations (Reimer-Kirkham et al. 2022; UN Human Rights Council, 2019a). A four-year ethnographic project in Tanzania, South Africa, and Ghana (pending) has provided the context for this analysis of human rights practice, with four specific insights. Understanding these particularities is necessary to take up a contextual and vernacularized approach to human rights, to promote the safety and security of mothers impacted by albinism. The first lesson relates to the need for continued affirmation of personhood as foundational for human rights. The taken-for-granted principle of human rights doctrine is at the core of the social exclusions and violence faced by persons with albinism. Persons with albinism in certain parts of Africa have been viewed as less than human, which hinders the application of constitutional human rights frameworks. This underscores the need to reaffirm fundamental personhood and humanness in albinism-related human rights advocacy. Although they did not cite formal human rights frameworks, mothers impacted by albinism understood their entitlement to human rights as the right to human dignity and to be free from discrimination.

The second lesson relates to a paradoxical exclusion that can occur for persons impacted by albinism when African communal readings of human rights are applied. Rather than being included under an umbrella of communal interpretations of human nature, persons with albinism can be excluded because of a perceived threat they pose to the wellbeing of an interconnected community. Here, the mothers in our study leveraged traditional communal values around social inclusion through a construction of their own community where they belong and take identity. They were supported by albinism-related CSOs who mobilized community ambassadors in the social institutions of healthcare, education, and religion.

The third lesson with implications for human rights stems from the relatively rare condition of albinism and the absence of systematic data on attacks against persons with albinism. Proportionality is crucial in metering a response, and those countries that have mechanisms to deal with populations that are structurally vulnerable can bring albinism into existing policies and programmes (e.g., under the umbrella of disability services). Finally, the intersectional nature of human rights violations experienced by mothers impacted by albinism requires the application of multiple human rights instruments, both international and regional. Human rights practice in the context of albinism in Africa must account for these four lessons as part of the process of vernacularizing human rights. Accounting for these local particularities for the mothers in our study could result in the strengthening of human rights protection, and thereby contribute to the normative application of universal human rights.

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