The Convention on the Rights of Persons with Disabilities and South Africans with Albinism: A Commentary

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Abstract

The year 2021 marks the fifteenth anniversary of the Convention on the Rights of Persons with Disabilities (CRPD). The enactment of the instrument has been lauded as ground-breaking, as it contains provisions that seek to safeguard the world's largest minority group, persons with disabilities (PwDs). The instrument is perceived as having triggered normative and institutional safeguards at the national, regional, and international levels with the aim of empowering this population. Despite this progress, it is apparent that a subgroup, namely persons with albinism (PwAs), are yet to reap the befits of the instrument. Among the mythologies of South African communities is the superstition that the body parts of these individuals possess magical powers which could be a source of fortune, lead to a bumper harvest, or cure complicated illnesses. Though these perceptions are erroneous, they lead some people to rape PwAs or to harvest their organs for rituals. As the international community celebrates the birth of the CRPD, this article argues that it is high time the state formulated a comprehensive intervention to avert further attacks on this vulnerable population.

Keywords: albinism; culture; Convention on the Rights of Persons with Disabilities; South Africa; persecution



Introduction

In African communities, superstitions are a key instrument in shaping people's aspirations and views. They can be used to foster affability, hospitality, and reconciliation. Alternatively, they can become a weapon of social disintegration and the alienation of groups considered undeserving. This is the plight of persons with albinism (PwAs) in post-apartheid South Africa. On 9 June 2020, three men pleaded guilty to the murder and mutilation of the body of a teenage girl with albinism. In another municipality, a traditional healer was sentenced to life for the murder of a woman with albinism, whose body parts were removed for rituals. These atrocities are but a few examples of the cruel and degrading treatment PwAs encounter in their daily lives. This abuse is perpetrated based on erroneous superstitions regarding skin complexion.

In South Africa, prejudice on the grounds of skin pigmentation is not a new phenomenon.⁴ However, whereas core indigenous systems and traditional beliefs ought to advance the wellbeing of vulnerable people in societies, in contemporary South Africa these beliefs seem to perform the opposite role. And while there have been reported cases of aggression and prejudice against PwAs, there is still a paucity of research on how the daily lives of this sub-population are shaped by their medical condition, what the sociocultural barriers are that exist, what action has been taken and what action ought to be taken to safeguard them from further persecution.⁵

It is against this backdrop that this article interrogates the prospect that the Convention on the Rights of Persons with Disabilities (CRPD) could be used as a means of advancing the rights of this vulnerable group. The article begins by surveying some of the complex challenges faced by PwAs. It then traces the significance of international and regional human rights instruments in promoting the rights of this group. It draws from the normative framework and jurisprudence of regional human rights bodies to advance arguments for effective interventions to safeguard the lives and dignity of the target group. It concludes by arguing that although courts could play an important role by obliging the state to strengthen security for this population, the ultimate remedy for averting albinism-related hostilities is demystifying albinism. It argues that there ought

¹ Mthobisi Mkhaliphi, 'The Suspects in a Mpumalanga Albino Teen's Murder to Appear in Court' (*SABC News*, 9 June 2020) https://www.sabcnews.com/sabcnews/the-suspects-in-a-mpumalanga-albino-teens-murder-to-appear-in-court/ accessed 23 March 2021.

² Bongani Mthethwa, 'Traditional Healer Given Life for Muthi Murder' (*Times Live*, 22 February 2017) https://www.timeslive.co.za/news/south-africa/2017-02-22-traditional-healer-given-life-for-muthi-murder/ accessed 23 March 2021.

Julie Taylor, Caroline Bradbury-Jones, and Patricia Lund, 'Witchcraft-Related Abuse and Murder of Children with Albinism in Sub-Saharan Africa: A Conceptual Review' (2019) 28 Child Abuse Review 13.

⁴ Cornel Verwey and Michael Quayle, 'Whiteness, Racism, and Afrikaner Identity in Post-Apartheid South Africa' (2012) 111(445) African Affairs 551 at 553.

⁵ Mkhaliphi (n 1); Mthethwa (n 2).

to be a fundamental shift in attitudes, which could be attained by raising awareness around albinism as a rare medical condition rather than a mystic phenomenon.

Living with Albinism

Skin colouration is often genetic or influenced by socioecological factors. While skin complexion has no direct effect on one's capabilities, it has been the basis of discrimination and suppression for centuries.⁶ At the peak of apartheid, in the early 20th century, skin colour was the basis for identifying a person's identity and race.⁷ This racial divide drew a wedge between and eroded bonds of social solidarity among different groups in society. As derogatory undertones were attached to (skin) colours, social identity evolved as inferior or superior. The concept of 'blackness', on the one hand, was perceived as 'impure' and thus inferior.^{8,9} On the other hand, 'whiteness' was associated with purity, and was therefore superior.¹⁰

Skin tone thus became the social and physiological foundation on which racial inferiority and superiority were erected. In effect, the social ladder was composed of whiter skin complexions (Afrikaners and Europeans) at the upper level, darker skins (Africans) at the bottom, and those with mixed coloration (Asians, Coloureds, and Indians) in-between. Codified in a plethora of segregationist (now repealed) statutes, access to and participation in political and socio-economic affairs in this era were mainly determined by one's skin colour. With the promulgation of statutes such as the Black Administration Act 38 of 1927, the Population Registration Act 30 of 1950, and the Riotous Assemblies Act 17 of 1956, the majority of the black population was relegated to manual labour. In contrast, the white minority enjoyed fundamental privileges in terms of land allocation, basic services, and social benefits. This phenomenon arguably informed the construction of the phrase 'white privilege' to illustrate the societal and institutional benefits accorded to one based on the lightness or darkness of one's complexion.

Werna M Keith and Cedric Herring, 'Skin Tone and Stratification in the Black Community' (1991) 97(3) American Journal of Sociology 760 at 761.

⁷ Jeremy Seekings, 'The National Party and the Ideology of Welfare in South Africa under Apartheid' (2020) 46(6) Journal of Southern African Studies 1145 at 1148.

⁸ Hermann Giliomee, 'The Making of the Apartheid Plan, 1929–1948' (2003) 29(2) Journal of Southern African Studies 373 at 386.

⁹ Richard A Wasserstrom, 'Racism, Sexism, and Preferential Treatment: An Approach to the Topics' (1976) 24(3) UCLA LR 581 at 592.

¹⁰ ibid.

¹¹ Seekings (n 7).

¹² Craig Charney, 'Class Conflict and the National Party Split' (1984) 10(2) Journal of Southern African Studies 269 at 273.

¹³ ibid.

¹⁴ Zeus Leonardo, 'The Color of Supremacy: Beyond the Discourse of "White Privilege" (2004) 36(2) Educational Philosophy and Theory 137.

It was in this light that Langa J argued that injustices perpetrated against a section of society based on their colour ought not to be repeated in the democratic South Africa. Ironically, as the torch of the apartheid era (norms and institutions) was passed on to the new democratic era, so were vengeance and retaliation, which many have harboured over injustices suffered during the past regime. This deep underlying resentment has fuelled hostility between groups with different complexions. This new atmosphere of antagonism has directly contributed to the disintegration of fundamental social values, inter alia *ubuntu*, which may simply be described as humanness, or respect for human life and the dignity of others. Ir

In the foregoing, a reader might discern that PwAs are absent from the racial classification and discussion. Why is this so? In answering the question simply, skin complexion and race are not inextricably linked. In other words, skin colour rarely defines one's race or ethnicity. PwAs tend to have pale skin, hair, and eyes, which distinguish them from others. ¹⁸ For this reason, PwAs do not neatly fit into the racial categories listed above. In the quest for identity and recognition, PwAs are confronted with widespread prejudice, stereotyping, and violent attacks due to erroneous superstitions. But before delving into the living conditions of this group, there is a central question that needs to be answered: What is albinism?

Albinism may be broadly categorised as a form of disability. In a narrower sense, it may be construed as a genetic condition triggered by the production of insufficient melanin in the body. While there is contestation on the exact number of PwAs in South Africa, it is speculated that 1 in 4 000 individuals live with the condition. Presently, the survival of the group is threatened on three fronts: health, exclusion, and insecurity.

Health

From a medical perspective, there are different kinds of albinism. The most common form is oculocutaneous albinism. PwAs experience two main impairments: (i) they are extremely sensitive to the harmful impact of the sun's ultraviolet radiation (UVR) on their skin; and (ii) they are visually impaired. The impairments may be traced to the inadequate pigment, or the lack of pigment, in their eyes, skin, and hair. Insufficient pigmentation means that harsh sunlight could potentially trigger skin cancer or exacerbate eye conditions. As a consequence, PwAs often need optical correction, as

¹⁵ S v Makwanyane 1995 (3) SA 391 (CC) para 24.

¹⁶ Jean Pierre Misago, 'Political Mobilisation as the Trigger of Xenophobic Violence in Post-Apartheid South Africa' (2019) 13 International Journal of Conflict and Violence 1.

¹⁷ *Makwanyane* (n 15) para 144.

¹⁸ Bright Nkrumah, "Hunted like Animals": The Conundrums of Countering Crimes against Albinistic Persons in the Era of the UDHR' (2018) 55 International Journal of Law, Crime and Justice 52 at 53.

Juliet Lapidos, 'How Many Albinos Are in Tanzania?' (Slate, 6 January 2009) https://slate.com/news-and-politics/2009/01/how-many-albinos-are-there-in-tanzania.html accessed 23 March 2021.

²⁰ Taylor (n 3).

²¹ Nkrumah (n 18).

their condition could result in refractive errors, photophobia, reduced visual acuteness, or reduced vision. Suffice it to note that this unique health condition could have dire economic consequences in terms of livelihood, as those with acute conditions are unable to pursue professions that bring them in close contact with the sun. Thus, the medical condition of PwAs could be exacerbated in communities where poverty and insufficient government interventions do not afford them access to sunscreen or timely medical care of pre-cancerous lesions.

Exclusion

The plight of the group is further exacerbated by major social factors. Although albinism transcends race, the social impact of the condition is more acute in African communities. as their light-toned skin makes PwAs distinct from others. One PwA recounts that others (non-disabled peers) did not 'like to touch me, saying that if they touched me, they would get this colour.'22 Negative perceptions have thus resulted in the exclusion of the group from different aspects of social engagement. Ultimately, marginalisation militates against living a fulfilling life, which encompasses satisfying the basic needs of human beings.²³ This societal challenge is faced by three types of PwAs: (i) children, who are unable to participate in outdoor activities due to the risk of sunburn; (ii) adults in a corporate environment, who are subjected to discrimination by their colleagues and superiors; and (iii) the disproportionate percentage of PwAs who are unemployed or who cannot pursue outdoor occupations due to their vision needs and skin sensitivity. While all three categories face some form of alienation, the fate of the last is somewhat dire, as deprivation could exacerbate one's marginalisation in society. As in traditional African communities, unemployment hinders one's fortunes in the marriage market, as the families of potential partners are often hesitant to approve of an underprivileged suitor. One PwA bemoans that '[o]ften I hear gossips, people backbiting at your back, saying "Why did he marry an albino? Maybe I have charmed him!" Even where this bridge is successfully crossed, deprivation could create tension, which often leads to separation or divorce. ²⁵ In light of this, some PwAs remain unmarried for a considerable period.²⁶ Ironically, remaining a single adult has an impact on successful integration, as some traditional societies frown upon divorce or the unwedded.

^{22 &#}x27;Surprise of Tanzania's Albino MP' (BBC News, 30 April 2008) http://news.bbc.co.uk/2/hi/africa/7348528.stm accessed 23 March 2021.

²³ Len Doyal and Iain Gough, 'A Theory of Human Needs' (1984) 4(10) Critical Social Policy 6 at 12.

²⁴ AD Ikuomola, 'Socio-cultural Conception of Albinism and Sexuality Challenges among Persons with Albinism (PWA) in South-West, Nigeria' (2015) 4(2) International Journal of Arts and Humanities 189 at 197.

²⁵ Alex Addae-Korankye, 'Causes of Poverty in Africa: A Review of Literature' (2014) 3 American International Journal of Social Science 150.

²⁶ Charlotte Baker, Patricia Lund, Richard Nyathi, and Julie Taylor, 'The Myths Surrounding People with Albinism in South Africa and Zimbabwe' (2010) 22(2) Journal of African Cultural Studies 169 at 176.

Insecurity

Sadly, exclusion remains the least of the concerns faced by this group. Absurdly, there is a conventional stereotype according to which PwAs are mystical beings and their body parts could be a source of fortune. In communities where this superstition is rife, persons with the condition are hunted and murdered for their body parts. At the time of writing, in March 2021, South Africa had recorded four killings, two PwAs had been reported missing, two had survived attacks, and one grave robbery had taken place. As illustrated in Table 1, these aggressions are pervasive in thirty countries. It is important to underscore that the nature of the violent attacks against victims strips them of their dignity and humanity, which are core tenets of African values. To be exact, victims are subjected to vicious attacks in the form of sharp objects used to hack their breasts, genitals, and limbs. It is speculated that this cruel treatment is exerted on a living being, as the pain experienced by the victim enhances the potency of the traditional charm (*muthi*).²⁷ The heinous process of taking the life of a PwA deprives a person of the honour he or she deserves, even on the verge of death.

²⁷ Nkrumah (n 18).

Table 1: Detailed breakdown of reported hostilities against PwAs in Africa, 2021

Countr	Mur	Missing	Survivors	Abandone	Asylum	Grave	Total
y	ders	persons	of attacks	d children	seekers	robberie	reports
						S	
BE	5	7	5	—	—	1	18
BT			3	—	—		3
BF	9		6	—	1		9
BR	22		13		_	4	39
CR	2		2	—	6	1	11
DRC	17	1	35	—	7	10	70
EG				—	1		1
GB			1	_	_		1
GH	1		2	_	_		3
GU	5		6	_	5		16
IC	9	4	13	2	2		30
KY	5		8	_			13
LE	1			_			1
MD	1		_	_			1
MW	18	5	26	_		7	56
ML	5	2	3	_	7		17
MZ	17	15	14	_		5	51
NM	2		2	_			4
NG		1	_	_			1
NI	4	1	3	_	5		13
RW				_		1	1
SN	3		4	_	2		9
SA	4	2	2	_		1	9
SW	4		8	_			12
TA	76	1	93	_	3	25	198
TO	1	_			_	_	1
UG	—	_	8		1	_	9
USA	—	_	2			_	2
ZM	9		7			2	18
ZI	1				1		2

Source: Under the Same Sun, 'Reported Attacks of Persons with Albinism' (24 March 2021)https://www.underthesamesun.com/sites/default/files/Attacks%20of%20PWA%20-%201%20page.pdf accessed 23 March 2021.

Note: The column heading 'Grave Robberies' refers to the desecration of graves of deceased PwAs. The corpses are exhumed and mutilated for rituals. The column heading 'Asylum seekers' refer to PwAs who have had to seek asylum in different countries as they fear for their lives. The abbreviations for country names in the first column: Benin, Botswana, Burkina Faso, Burundi, Cameroon, Democratic Republic of the Congo, Egypt, Gabon, Ghana, Guinea, Ivory Coast, Kenya, Lesotho, Madagascar, Malawi,

Mali, Mozambique, Namibia, Niger, Nigeria, Rwanda, Senegal, South Africa, Swaziland, Tanzania, Togo, Uganda, United States of America, Zambia, Zimbabwe

The effect of hostilities on children is most concerning, as they are unable to participate in outdoor activities at school or openly play with their peers. Most importantly, these acts of aggression impact on the group's access to (quality) education, which directly and indirectly affects their ability to secure employment and earn a living or be fully integrated into society. As a consequence, some parents and guardians take extra precautionary measures, including (i) sending their children to distant relatives in cities; (ii) placing them in boarding schools; (iii) relocating to safer communities; (iv) seeking protection from security agencies; (v) providing home education rather than allowing their children to attend community schools; or (vi) in extreme cases, accompanying their children to school and around their neighbourhood.

In light of these atrocities, the next portion of this article explores the rights of PwAs in regional, and (inter)national human rights instruments, with particular reference to skin colouration as the basis for discrimination and persecution.

The CRPD and the Rights of PwAs

Following the end of World War II, a plethora of international instruments emerged, all seeking to safeguard the rights of human beings. The first of these was the Universal Declaration of Human Rights (UDHR). Apart from the Preamble, the instrument contains thirty articles with diverse yet interrelated rights. The most significant of these are the rights to life, equality, non-discrimination, and freedom from cruel and inhuman treatment. Over the last seven decades, these rights (along with others) have birthed a myriad of international instruments which seek to shape and advance the rights of vulnerable populations. A few of these instruments are the International Covenant on Civil and Political Rights, the International Covenant on Economic, Social and Cultural Rights, and the Convention against Torture and Other Cruel, Inhuman or Degrading Treatment or Punishment.

At the regional level, the African Charter on Human and Peoples' Rights could be perceived as the most authoritative instrument for guaranteeing rights. By becoming a party on 9 July 1996, South Africa guaranteed the right of persons with albinism to benefit from the right to life, set out under article 4 of this Charter. The right to life may be pictured as the fulcrum around which all other rights revolve, particularly as it is inextricably tied to the spiritual, ethical, and physical existence of humankind. The

²⁸ International Covenant on Civil and Political Rights (adopted 16 December 1966, entered into force 23 March 1976) 999 UNTS 171 (ICCPR).

²⁹ International Covenant on Economic, Social and Cultural Rights (adopted 16 December 1966, entered into force 03 January 1976) 993 UNTS 3 (ICESCR).

³⁰ Convention Against Torture and Other Cruel, Inhuman or Degrading Treatment or Punishment (adopted 10 December 1984, entered into force 26 June 1987) 1465 UNTS 85 (CAT).

African Charter on the Rights and Welfare of the Child (ACRWC)³¹ and the Protocol to the African Charter on Human and Peoples' Rights on the Rights of Women in Africa (the Maputo Protocol)³² were forged to safeguard two of the continent's most vulnerable populations, namely women and children. Both instruments emerged out of mutual consensus that their respective mother treaties did not adequately capture the unique challenges faced on the African continent.³³ To this end, the ACRWC and the Maputo Protocol were adopted to provide adequate protection for women and children against abuse suffered due to patriarchy and harmful cultural practices.

Regardless of the significance of these instruments, the cardinal (regional) instrument which specifically speaks to South Africans with albinism is the Protocol to the African Charter on Human and Peoples' Rights on the Rights of Persons with Disabilities (PRPD). By echoing similar sentiments to those expressed by the CRPD, the document illuminates the unique challenges faced by people with disabilities (PwDs) in Africa. Article 9(3) of the PRPD specifically obliges state parties to safeguard PwDs from abuse and to prosecute the perpetrators of such abuse. To that end, Article 12(a) enjoins state parties to '[t]ake specific measures to ensure the protection and safety of persons with disabilities in situations of risk.' Yet, despite the noble intentions of the instrument, it falls short on two grounds: (i) it fails to explicitly address stereotypes and harmful cultural practices perpetrated against PwAs; and (ii) it has still not entered into force, and is therefore not binding. To that end, the potency of the PRPD in addressing violence against PwAs remains questionable.

Since these instruments fail to sufficiently guarantee the rights of PwDs, the international community adopted the CRPD.³⁵ This instrument, which entered into force in 2008, is the first international treaty to be adopted in the 21st century. The CRPD is also the first binding instrument to explicitly guarantee the rights of one-fifth of the world's population who experience some form of disability.³⁶ One of the groups whose rights are guaranteed is PwAs, as their impairment is a form of disability.³⁷ In justifying this claim, perhaps it is important to clearly define disability. A disability may be linked

³¹ African Charter on the Rights and Welfare of the Child (adopted 11 July 1990, entered into force 29 November 1999) CAB/LEG/24.9/49 (ACRWC).

³² Protocol to the African Charter on Human and People's Rights on the Rights of Women in Africa (adopted 11 July 2003, entered into force 25 November 2005) (Maputo Protocol).

³³ Convention on the Elimination of All Forms of Discrimination against Women (adopted 18 December 1979, entered into force 3 September 1981) 1249 UNTS 13 (CEDAW); Convention on the Rights of the Child (adopted 7 March 1990, entered into force 2 September 1990) 1577 UNTS 3 (CRC).

³⁴ Protocol to the African Charter on Human and Peoples' Rights on the Rights of Persons with Disabilities in Africa (adopted 29 January 2018).

³⁵ Convention on the Rights of Persons with Disabilities (adopted 13 December 2006, entered into force 3 May 2008) A/RES/61/106 (CRPD).

³⁶ World Bank, 'Disability Inclusion' https://www.worldbank.org/en/topic/disability accessed 23 March 2021.

³⁷ *Y v Republic United of Tanzania* Communication 023/2014 (Final decision adopted on 31 August 2018).

to the physical, mental, and structural constraints that persons with impairment encounter given the structures of society.³⁸ Impairment, on the contrary, refers to inability or limited functioning of any part in a person's body structure or mental functioning.

The constraints faced by a PwD may extend to attitudinal, sociocultural, material, or physical elements which might inhibit the person's participation in everyday life. The self-esteem of PwAs is affected, as they are feared, antagonised, or continuously shunned by others. This constraint may trigger 'disabilism', a phenomenon where one is exploited based on one's impairment.³⁹ Thus, as its name reflects, the cardinal aspiration of the CRPD is to empower, among others, PwAs to reclaim their inherent right to equality, non-discrimination, and freedom from systemic persecution. A cursory overview of the instrument indicates that it complements preceding instruments which seek to safeguard fundamental rights, particularly those of vulnerable populations.

Perhaps one of the most significant elements of the CRPD is its sociological, rather than medical, conceptualisation of disability. Article 1 of the instrument frames disability as the undesirable engagement between a person with an underlying health condition and other artificial or natural factors which limit the person's active engagement in social affairs. It includes the relationship between the person and their surroundings. In reaffirming PwDs as rights holders and equal members in all societies, Article 1 of the instrument broadly defines a PwD as any individual with long-term sensory, intellectual, and mental impairment that might limit their social interaction, particularly in light of dominant challenges in societies. However, this definition has attracted two schools of thought. According to the first camp, this narrow definition will provide benchmarks for states in determining who falls within the disability spectrum. According to the other camp, this explicit definition may be short-sighted, as new forms of impairment may evolve which do not fall with the three thresholds listed (sensory, intellectual, and mental).

These contentions notwithstanding, an important aspect of the CRPD is that it calls on states to not arbitrarily deprive PwDs of the fundamental right to life. In effect, Article 10 of the CRPD enjoins member states to frame and operationalise effective

³⁸ Deborah Kaplan, 'The Definition of Disability: Perspective of the Disability Community' (2000) 3(2) Journal of Health Care Law & Policy 352 at 356.

³⁹ Katherine Runswick-Cole, 'Living with Dying and Disabilism: Death and Disabled Children' (2010) 25(7) Disability & Society 813 at 824.

⁴⁰ Paul Harpur, 'Embracing the New Disability Rights Paradigm: The Importance of the Convention on the Rights of Persons with Disabilities' (2012) 27(1) Disability & Society 1 at 3; Frédéric Mégret, 'The Disabilities Convention: Human Rights of Persons with Disabilities or Disability Rights?' (2008) 30 Human Rights Quarterly 494 at 495.

⁴¹ Arlene Kanter, 'The Promise and Challenge of the United Nations Convention on the Rights of Persons with Disabilities' (2007) 34 Syracuse Journal of International Law and Commerce 287 at 291; Aart Hendriks, 'UN Convention on the Rights of Persons with Disabilities' (2007) 14(3) European Journal of Health Law 273 at 276.

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interventions to safeguard PwAs and similarly situated individuals from atrocities in light of their physical or mental condition.

Linked to human life is the right to fairness and non-discrimination. Article 2 of the CRPD succinctly articulates 'discrimination' as any form of marginalisation or restriction imposed with the intent of hindering the fulfilment of a person's basic rights. To attain substantive equality for PwDs, Article 5 of the CRPD calls for the elimination of all forms of prejudice that fuel discrimination and targeted attacks against PwDs, including PwAs. The instrument specifically enjoins states to use reasonable measures to eliminate attitudinal barriers and harmful superstitions which perpetuate the stigmatisation and vulnerability of people with health conditions.

A state's compliance with the CRPD could be assessed on five levels: (i) the degree to which ratified states amend existing laws or frame new ones to reflect the provisions of the instrument; (ii) the establishment of effective institutions to operationalise the listed rights; (iii) the dissemination and publication of the instrument to raise awareness of the rights to be claimed; (iv) the establishment of an effective judicial system to enable victims to seek redress; and (v) the extent to which security agencies are strengthened to provide adequate protection for PwAs and others in similar situations. Failure to undertake these five steps may constitutive a breach of the fifty articles stipulated in the CRPD. And, finally, judicial bodies must be empowered to perform efficient monitoring and oversight duties.

It was against this backdrop that the Committee on the Rights of Persons with Disabilities lamented that a state party infringed on Article 5 of the CRPD when it failed to provide adequate security for PwAs. ⁴² The Committee argued that the ongoing attacks and the state's inaction equally breached Article 7 (full enjoyment of rights), Article 8 (combatting stereotypes), Article 10 (the right to life), and Article 16 (freedom from abuse) of the treaty. ⁴³ It was specifically concerned on four grounds: (i) insufficient awareness campaigns around albinism as a medical condition; (ii) insufficient security for persons with the condition; (iii) failure to conduct investigations into reported abuses; and (iv) a lack of remedies for victims of abuse. ⁴⁴ The decision of the Committee was a landmark decision on two levels: by invoking Article 5, the Committee affirmed the conventional wisdom of 'colour' as grounds of discrimination, and by granting admissibility and adjudicating on the application, it placed the stamp of 'disability' on albinism.

In terms of application, section 231 of South Africa's Constitution stipulates that an international law such as the CRPD could become binding on the state in one of two instances: if it is self-executing, or if it is approved by the National Council of Provinces and the National Assembly. Section 232 proceeds to affirm that customary international

⁴² Y v Tanzania (n 37).

⁴³ ibid para 9.

⁴⁴ ibid.

laws are directly applicable unless such instrument contains provisions that are an affront to local legislation, primarily the Constitution. Section 233 further enjoins judges to consider international instruments and jurisprudence in providing interpretations to the Bill of Rights. These provisions make the CRPD crucial in the preservation of the rights of PwAs, especially in seeking judicial remedy or in approaching the government to provide sufficient protection for the vulnerable population. Thus, when it ratified the CRPD in November 2007, South Africa was enjoined to avert and investigate violent attacks against PwAs, and to prosecute the perpetrators of such attacks.⁴⁵ As South Africans with medical conditions may struggle to identify with a particular race, the Constitution specifically refers to skin 'colour' as a reference for non-discrimination.

In echoing the provisions of the International Covenant on the Elimination of All Forms of Racial Discrimination, section 9(3) of the Constitution specifically avers that the state ought not to directly or indirectly discriminate against, exclude, or restrict any person based on their skin colour. It affirms that this form of marginalisation hinders the realisation of one's civil/political and socio-economic rights. The insertion of colour in the instrument may be seen as an attempt by the drafters to address any confusion which might arise based on a person's descent and physical appearance, particularly in the framing of affirmative action or the redress of exclusion. This hypothesis was tested in 2007 when an ethnic Asian community alleged that not only were they excluded during the apartheid era due to their classification as mixed-raced, they faced similar exclusion (from job promotions and government contracts) in contemporary South Africa due to their re-classification as whites. 46 In navigating the puzzling interaction between a person's appearance and the social dynamics associated with appearance and skin colour, the court held that members of the group ought to be recategorised as blacks and accorded the necessary privileges. The ruling suggests that while race and skin complexion may overlap, they are quite distinct. For while the former flows from descent and ethnicity, the latter could be misleading, as some people of African descent might be light-skinned, seemingly 'white' in appearance. Thus, while belonging to the same race as Africans, some may receive preferential treatment (in appointments, housing, and social status) thanks to their (fair) skin complexion. It is in light of these dynamics that section 9(3) of the Constitution guarantees the right to equality and nondiscrimination regardless of one's race or skin colour.

Of particular importance to PwAs is section 12(1) of the Constitution, which enjoins the state to safeguard them from all forms of cruel and inhuman treatment, perpetrated by either the state or third parties. It is against this backdrop that the Bill of Rights enjoins the state to respect, protect, promote, and fulfil the right to life of PwAs and similarly

⁴⁵ See the ratification status of South Africa at https://tbinternet.ohchr.org/_layouts/15/TreatyBodyExternal/Treaty.aspx?CountryID=162&Lang=E N> accessed 22 March 2021.

⁴⁶ Chinese Association of South Africa and Others v Minister of Labour and Others (59251/2007) [2008] ZAGPHC 174. Case number 59251/2007.

situated individuals.⁴⁷ Under the rubric of the right to life, the state has a positive obligation (to safeguard its citizens from life-threatening attacks by private individuals) and a negative obligation (to restrain its institutions from perpetrating such crimes).⁴⁸ Thus, in light of the widespread attacks perpetrated against these vulnerable South Africans, a reader could rightly argue that extra precautionary measures ought to be framed and operationalised by the state. This observation was echoed by the European Court of Human Rights when it stated that the positive obligation of a state transcends the mere establishment of security apparatus to deter perpetrators of violent crimes.⁴⁹ To the court, this obligation is only complied with when the state ensures such institutions are effective, well resourced, and timeously deployed for the deterrence of such atrocities. 50 This reasoning was adopted by the South African Constitutional Court three years later, when it held that while the police have the primary obligation of protecting all civilians, it ought to, in some instances, exercise due diligence.⁵¹ The notion of due diligence may be construed as exhausting all available measures to avert an infringement, and when that violation still occurs, the state may not be held liable. In effect, the security cluster has the primary duty of taking proactive measures to safeguard vulnerable sections of society, particularly women and children. In sum, the best illustration of due diligence is based on the prevention of attacks.

Constraints to Effective Operationalisation of the CRPD

While the CRPD and the South African Constitution seek to safeguard PwAs from targeted attacks, the effective operationalisation of these instruments has been slow. This setback may be ascribed to six distinct but related factors: (i) a lack of visibility; (ii) a lack of political will; (iii) the neglect of albinism in policy circles; (iv) insufficient awareness campaigns; (v) greed and/or poverty; and (vi) gender and generational vulnerability.

Despite the resurgence of albinism-related crimes, scholarship exploring the deleterious impact of culture on the lived experiences of PwAs is scarce. This is even more true in South Africa, where the persecution of PwAs has attracted little debate in the media and policy circles. The dearth of literature in this sphere may be tied to the group's relatively small number, which has exacerbated their marginalisation in various communities. They are, in effect, voiceless and a constant target for abuse. It is crucial to note that the lack of visibility around these atrocities has three negative repercussions: (i) it undermines efforts towards advocating for the group's security and wellbeing; (ii) the

⁴⁷ Richard Goldstone, 'The South African Bill of Rights' (1997) 32 Texas ILJ 451 at 456.

⁴⁸ George P Fletcher, 'The Right to Life' (1979) 13(4) Georgia LR 1371 at 1377.

⁴⁹ Osman v the United Kingdom 29 EHHR 245 para 115.

⁵⁰ ibid.

⁵¹ Carmichele v Minister of Safety and Security 2001 (4) SA 938 (CC).

abuse of this group continues to be disregarded; and (iii) it leads to a lack of international or social pressure to deter perpetrators.

A lack of political will is another contributing factor. Despite the ratification of the CRPD and other international instruments purporting to protect the rights of PwAs, actual policy interventions in South Africa have been inadequate. For instance, on 16 June 1995, South Africa became a party to the Convention on the Rights of the Child (CRC).⁵² The country is thus obliged to exercise due diligence in safeguarding young people from violent attacks. Other regional and international organisations have also called on South Africa and other countries where albinism-related crimes are rife to strengthen efforts to curb these crimes. At the continental level, the African Commission on Human and Peoples' Rights has amended its state reporting process by obliging member states to specifically indicate in their reports the current state of affairs relating to PwAs, as well as specific legislative and institutional measures taken to safeguard the population.⁵³ On the international level, the United Nations has taken three important steps in this regard: (i) appointing an independent expert on the enjoyment of human rights by persons with albinism; (ii) declaring 13 June International Albinism Awareness Day; and (iii) vehemently calling on states to undertake sustainable interventions to avert the persecution of PwAs.⁵⁴ National and subnational interventions have been marked by political condemnation and promises; however, at the time of writing, in early 2021, there was still no specific policy or programme specifically tailored to promoting awareness or boosting security for PwAs. It is therefore fair to presume that the state does not have the will to safeguard this group. This hypothesis is confirmed by the fact that despite exercising absolute autonomy over security agencies and public media, the state has still not deployed these resources towards effective campaigns and the protection of PwAs.

Albinism is neglected in policy circles. Presently, there is no statute or specific institution established to address the unique challenges faced by PwAs. The only document which speaks to the plight of PwAs is a 2013 Declaration adopted by a group of PwAs and activists. Termed the Ekurhuleni Declaration on the Rights of Persons with Albinism, the document contains forty paragraphs and begins by proclaiming the inalienable rights of PwAs. It then proceeds to define albinism as a genetically inherited, non-contagious medical condition that results in insufficient pigmentation in the eyes, skin, and hair. It notes the erroneous superstitions around this medical condition, and describes the lived experiences of individuals with the condition. The document then bemoans the insufficient efforts by the state in tackling discrimination, and details how the state's inaction infringes on Article 8 of the CRPD (combating stereotypes and

⁵² Note 33.

⁵³ African Commission on Human and Peoples' Rights, '263 Resolution on the Prevention of Attacks and Discrimination against Persons with Albinism' ACHPR/Res.263(LIV)2013 https://www.achpr.org/sessions/resolutions?id=283 accessed 22 March 2021.

⁵⁴ UN, 'International Albinism Awareness Day: 13 June' https://www.un.org/en/observances/albinism-day accessed 23 March 2021.

harmful practices).⁵⁵ One fundamental section of the document relates to the resolutions on the protection of this group. The document sets out three important resolutions: (i) it calls on the state to develop new instruments or to strengthen existing ones to enforce the rights of PwAs; (ii) it calls on the South African Human Rights Commission (SAHRC) to compile a register of abuses perpetrated against the group; (iii) it calls on the SAHRC to conduct investigations and surveys into violent attacks against PwAs, including human trafficking and infanticide. Strikingly, nearly a decade since the adoption of this resolution, the explicit albinism-related policy has not been codified or operationalised. Furthermore, the SAHRC has not yet engaged in detailed reporting on the trends regarding abuses. In summary, the inaction of the state and the SAHRC in this regard makes it difficult to determine the extent to which this group is being persecuted, where the hotspots are, and what the required remedy is.

Another factor is insufficient awareness campaigns. Folklore, inflamed by insufficient knowledge around albinism, has been the driving factor behind the persecution of this group. Ironically, the lack of information about this medical condition is prevalent not only among persons without albinism, but also in the communities in which PwAs live. For instance, young people with the condition believe that their pale skin is due to the erosion of the top layer of black skin, which exposes the second, white layer. This misconception could affect their social interaction, as they may perceive themselves as unfit in ordinary society. Simply put, if children are misinformed regarding their medical condition and/or identity, they might eventually come to accept the widespread myths which undermine their dignity and humanity in society.

The next factor is greed and/or poverty. One of the cardinal motivations for albinism-related kidnapping and murder has been attributed to the state of poverty in the country. It is speculated that on the black market, the complete set of body parts (nose, tongue, ears, four limbs, and genitals) are often traded for approximately USD75 000 (approximately ZAR1 million).⁵⁷ The high price may be attributed to the status of the persons who engage in these practices, as there have been reports of politicians and affluent individuals relying on these body parts to secure electoral victory, improve their businesses, or increase their sexual prowess. Ultimately, the prospect of financial returns has attracted a considerable number of predators, and in some instances family members become complicit in the murders.

⁵⁵ South African Government, 'Ekurhuleni Declaration on the Rights of Persons with Albinism' (27 October 2013) https://www.gov.za/ekurhuleni-declaration-rights-persons-albinism# accessed 21 March 2021.

⁵⁶ Patricia Lund, 'Living with Albinism: A Study of Affected Adults in Zimbabwe' (1998) 63 Social Biology and Human Affairs 3 at 7.

⁵⁷ International Federation of Red Cross and Red Crescent Societies, 'Through Albino Eyes: The Plight of Albino People in Africa's Great Lakes Region and a Red Cross Response' (2009) https://www.ifrc.org/Global/Publications/general/177800-Albinos-Report-EN.pdf accessed 23 March 2021.

The final factor is gender and generational vulnerability. Although all PwAs are equally vulnerable, some are in greater danger than others. On the one hand, men with albinism might have the physical strength to fend off their attackers and they are less likely to be sexually abused; they also do not run the risk of having their chests mutilated for the preparation of *muthi*. Women and children, on the other hand, face grave intersectional threats based on their inability to ward off their attackers. Furthermore, women or girls with albinism are more likely to be raped due to the misperception that sexual intercourse could cure the perpetrator of HIV/AIDs. Finally, the female breast happens to be one of the desired organs. Perhaps the preference for the breast is tied to its association with purity and life. According to Hogan, a woman's breast symbolises the life of an infant, as well as bonding between mother and child.⁵⁸

These prevailing atrocities committed against the wider community of PwAs ought to be addressed. The article now shifts its attention to strategies which could be operationalised to efficiently safeguard the group.

Towards the Effective Implementation of the CRPD

In seeking a holistic solution towards achieving the aspirations of the CRPD, and particularly towards averting violence against PwAs, seven strategies come to the fore. First, courts could deter attacks on PwAs by handing down hefty sentences for perpetrators. The severity of the punishment attached to albinism-related murder has the prospect of deterring potential attackers. Yet, filing complaints of abuse or violent attack could be financially burdensome, as people may have to travel to cities to attend court proceedings. Furthermore, as murder or attempted murder trials could be unduly prolonged, they could be seen as counterproductive for survivors of attacks and for rape victims, as time and resources will be required. It is therefore important for public interest litigators (PILs) who have committed themselves to assist the group to decentralise to local communities and make their services readily available to PwAs and similarly situated persons. PILs could draw on the overarching *locus standi* set out under section 38 of the Constitution to challenge the state's failure to exercise due diligence in safeguarding PwAs. Such complaints could provide an opportunity for the court to intervene, particularly in terms of exerting pressure on the state to boost police presence in communities where attacks are rife.

The second strategy relates to the notion of smart power (SP). Power, in this context, may be construed as the ability of the state to achieve the desired result by influencing the conduct of its citizens.⁵⁹ The extent of power may be measured by the amount of resources a state wields and/or can utilise. By extension, power is operationalised or realised through the utilisation of some form of resource. It is important to underscore

⁵⁸ Susan Hogan, 'Breasts & the Beestings: Rethinking Breast-Feeding Practices, Maternity Rituals, & Maternal Attachment in Britain & Ireland' (2008) 10 Journal of International Women's Studies 142.

⁵⁹ Ernest J Wilson III, 'Hard Power, Soft Power, Smart Power' (2008) 616 ANNALS: AAPSS 110.

that not all resources are tangible. At the national level, the state may similarly rely on both tangible or intangible resources to either induce or coerce perpetrators to cease violent attacks against PwAs. This objective could be achieved through the application of SP. In principle, SP is the combination of soft and hard power. ⁶⁰ While soft power may be tied to the provision of incentives to induce one to act in a particular manner, hard power, on the contrary, is the use of coercion or aggressive strategies to alter negative behaviours. The use of hard power in this context could involve largescale crackdowns on perpetrators, by reinforcing investigation into the operations of persons believed to be associated with albinism-related rituals. This measure brings to bear the invocation of soft power. It would be crucial for the state to provide sufficient incentives—in the form of adequate salaries, an effective communication network, and a transport system—to enable these security agents to effectively conduct their operations.

Third, since superstitions are rarely changed or suppressed by the use of force, the role of opinion leaders is of paramount importance. In many urban and rural communities, certain actors have been noted as powerful voices in shaping the conscience of society. Often termed opinion leaders, these are charismatic and influential leaders who use their outstanding personal qualities to inspire and promote an ideal. To this end, the state could partner with influential figures to reconstruct erroneous beliefs around albinism. This holds for many communities, as a society often looks up to charismatic leaders for direction and guidance. The condemnation, by persons who possess moral authority, of atrocities against PwAs will give the group hope and a sense of belonging, identity, security, and warmth. Indeed, the strong conviction, unselfish devotion, and compelling articulation of the values and ideals of *ubuntu* could be the first step towards humanising and discarding the veil around albinism as a supernatural condition. By invoking the notion of *ubuntu*, opinion leaders could use existing traditional values as the grounds for attitudinal change. Indeed, the articulations of these actors might not stimulate immediate attitudinal change, but it could nurture positive images and promote understanding of the scientific and social dynamics of albinism. This form of activism is likely to boost the self-confidence of PwAs while increasing social pressure on perpetrators to cease their operations.

Fourth, the state ought to forge a strong alliance with relevant civil society organisations (CSOs). Indeed, the role of contemporary CSOs in shaping public perception cannot be underestimated. Drawing from their extensive experience in the human rights arena, these organisations can be instrumental at four levels: (i) disseminating information around albinism at the grassroots level; (ii) lobbying traditional leaders to be active in albinism-related campaigns; (iii) providing counselling services for PwAs, who constantly face discrimination, marginalisation, and physical threats in their local communities; and (iv) liaising with local private sector role players in providing skills development for interested participants, as a means of boosting their prospects of being

60 ibid.

self-sufficient. Given that poverty is one of the contributory factors of albinism-related murders, the provision of skills development in concerned localities is likely to reduce the number of perpetrators or family members who might be tempted to commit this crime. It is, however, important to note that this intervention may only lead to passive assent, as there have been instances of teachers and politicians engaging in the serious act of murdering PwAs.⁶¹

The fifth entry point lies in the participation of PwAs in key policy discussions. In Kenya and Tanzania, PwAs have been empowered to directly engage in parliamentary debates and decision-making; however, the same cannot be said about the group in South Africa. 62 A quick survey of the main actors responsible for the protection of PwAs will illustrate that PwAs are not represented among these actors, and/or that these actors have insufficient understanding of the medical condition itself. This deficiency undoubtedly impacts on the content of disability frameworks or on institutions that purport to address the specific health or social challenges of PwAs. While it may be argued that an able-bodied person could fairly advance the interests of PwAs, it might be useful to directly involve representatives of this group in the codification and operationalisation of albinism-related interventions. Including PwA representatives in leading policy interventions will create trust and confidence in the government effort, as the representatives would reflect the ideals, values, and vision of the PwA community. Moreover, their effective engagement would provide a platform for them to articulate their concerns and fears, which would ultimately play an important role in the adoption of a feasible and long-term solution.

Furthermore, in the age of social media, both print and electronic media can be a means to raise awareness around albinism as a medical condition rather than a superstition. Sadly, recent media reports around albinism offer limited insight on the medical condition, with little effort made to clarify that one parent with an albinistic gene could pass the gene on to his or her child, even though the parent might be dark-skinned. As a result, the birth of a child with the condition is sometimes perceived as the outcome of a mother's infidelity: Since the child has 'pale' skin (in contrast to the father's dark complexion), the assumption is that the mother engaged in an illicit affair with a white person, spirits, or carriers of the albinism gene. Sometimes, these children face the extra burden of being disowned by their fathers, resulting in the child being deprived of the basic support system of both parents. This setback ultimately leads to poverty, poor quality health care, and subsequent unemployment, as single mothers arguably find it

⁶¹ Promise Marupeng, 'Teacher Admits Chopping Up Teen Girl with Albinism' (*Sowetan Live*, 21 August 2019) https://www.sowetanlive.co.za/news/south-africa/2019-08-21-teacher-admits-chopping-up-teen-girl-with-albinism/> accessed 23 March 2021.

⁶² Adam Withnall, 'What It's Like to Be an MP in a Country Where Some People Think You're a Ghost' (*Independent*, 12 December 2016) https://www.independent.co.uk/news/world/africa/isaac-mwaura-albino-mp-kenya-albinism-tanzania-uganda-witchcraft-killings-a7470726.html accessed 13 April 2021; Fumbuka Ng'wanakilala, 'Tanzania's First Elected Albino MP Fears for Life' (*Reuters*, 15 November 2010) https://www.reuters.com/article/ozatp-tanzania-albinoss-20101115-idAFJOE6AE0D820101115 accessed 13 April 2021.

difficult to meet all the basic needs of the child. As a consequence, a concerted media focus is required to highlight the hereditary element of the genetic condition, to correct misconceptions, and to advocate proper medical care for PwAs.

Finally, classrooms could be an important arena for disseminating information and awareness campaigns. It is suggested that the Department of Basic Education include albinism in its curriculum, for what good will it serve an individual to receive all the relevant education and still have doubts about his or her identity or become a prey? The proposed course content could include basic information about the medical condition, the genetic component, how the condition is passed on, the effects of the condition, and how to manage these effects. As there are elementary schools in virtually all urban and rural communities, local teachers could play an extra role in enlightening community leaders and ordinary residents about the medical condition. Local teachers are bound to make a significant impact if given the needed information and support, particularly as they are revered and looked up to for guidance in traditional African society.

Conclusion

The central argument of this article is that PwAs face a myriad medical and psychosocial challenges. They are prone to visual impairment and cancer, and they encounter discrimination and stigmatisation in many South African communities. Since there are no specific human rights instruments tailored to protect their right to dignity, safety, and life, this article argues that PILs ought to rely on existing instruments, such as the CRPD and the Constitution, in calling for better protection for this sub-population. Reliance on these international instruments is essential, as South Africa is a party to the CRPD and is thus enjoined to implement legislative and institutional interventions to avert atrocities committed against the group. From the foregoing, it is evident that a more focused framework at the national and international levels is needed, as well as a concerted effort to address the stigmatisation of, prejudice against, and violent attacks against PwAs.

This article has made compelling arguments for awareness creation around the misconceptions of albinism, particularly through the involvement of major players such as teachers, opinion leaders, CSOs, and PwAs themselves. It argues that as long as society clings onto the misconception of 'white' and 'black' skins, efforts towards countering albinism-related persecution will be cumbersome. This will entail channelling sufficient efforts towards activism and using print and electronic media to conscientise local communities on the need to treat each person equally, regardless of his or her colour. The article argues that the judiciary has a primary role in safeguarding PwAs and ensuring their successful integration in societies. Judges' efforts may include handing down harsh punishments for perpetrators of violent attacks, holding the state accountable for failing to take appropriate measures to protect a (vulnerable) section of the population, and awarding adequate compensation to PwAs who suffer discrimination and violent attacks based on their condition. Yet, what good will

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compensation serve a corpse, or a person whose body parts have been traded? It is against this backdrop that the article strongly advocates proactive measures in forestalling atrocities rather than providing remedies for victims.

In sum, the article concludes by making five key recommendations: (i) rigorous awareness campaigns must be implemented to educate people about albinism; (ii) a community task force must be established for protecting PwAs; (iii) the SAHRC must report periodically on the living conditions of PwAs; (iv) the general public must be actively involved in safeguarding PwAs; and (v) security must be reinforced in hotspots of albinism-related crimes.

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