I'm not a robot

SEATTLE, Washington — In Africa, living with albinism can be a death sentence. Adults, teenagers but especially children and infants, fall victim to brutal attacks. The Journal of the American Academy of Dermatology found that genetically, Africans are more prone to albinism. According to a 2019 research study, albinism's prevalence in Africa is between one in 5,000 to one in 15,000. These numbers highlight the high incidence of this genetic diagnosis within the African continent. Unfortunately, Africa's high incidence of albinism exists among countries where it is most dangerous for them to live. Poverty-stricken, medically untreated and even hunted, those with albinism in Africa live in constant fear. What is Albinism? Albinism often references oculocutaneous albinism (OCA), a group of inherited genetic conditions that cause little to no production of melanin pigment. Melanin regulates the color of skin, hair and eyes. Types of albinism vary, but the most common medical impairments include vision and dermatological risks. Exposure to the sun can be highly damaging to both the skin and eyes. This is due to the diagnosed individual having significantly less pigmentation. Access to sunscreen, protective clothing and sunglasses are crucial needs for anyone living with albinism. Albinism in Africa Albinism in Africa is viewed differently across the continent's countries. For some communities in Tanzania, an Albino's body parts are believed to have minerals that bring wealth, luck and even sexual conquest. Some existing, but rare, healers conduct ritualistic practice using teeth, bones, genitals and other albino's body parts. Moreover, some groups believe albino body parts hold more power proportional to the victim's youth and how intense they scream, according to the Office of the U.N. High Commissioner for Human Rights. Alternatively, across sub-Saharan Africa, it is believed one can be cured of HIV/AIDS if one rapes and performs a ritualistic defilement on a young girl with albinism. In Zimbabwe, those living with albinism may be referred to as sope, meaning spirit or vengeful ghost. In this region, the lighter pigmentation of skin leads to the belief that evil spirits inhabit those living with albinism. Other stereotypes surrounding albinism in Africa include witchery, punishment for a sinful family and that a white man or the devil impregnated an albino's mother. Albinism not only severely endangers the person, but sometimes the mother, and in extreme cases, their entire family falls victim to hate crimes. Stigmas Surrounding Albinism and Affecting Human Rights Unfortunately, albinism in Africa has devastating risks well beyond those in westernized countries. The rampant stigma does not stop at community levels. Police and medical practitioners, such as midwives, let cultural stereotypes affect their practice. Local authorities are more likely to ignore albino hate crimes and kidnappings. Medical workers believing the stigmas associated with albinism leave those living with the condition untreated. Inadequate childbirth assistance, lack of medical treatment and discriminatory practitioners contribute to the higher death rate among those diagnosed with albinism in Africa. Although albinism in Africa is gaining attention globally, brutal events still take place every day. In Tanzania, Emmanuel Festo, an aspiring artist living with albinism, is but one of many victims. At age seven, Emmanuel was taken and brutally attacked while his mother was inside making dinner. These albino hunters dismembered the seven-year-old with machetes—the Office of the U.N. High Commissioner for Human Rights estimated that Emmanuel's arm would sell for approximately $2,000, or 4,634,000 Tanzanian Shillings on the black market. Albino hunters can go as far as selling an entire human corpse for up to $75,000. Albinism Affecting Poverty and Families People diagnosed with albinism in Africa find themselves with less protection than their local counterparts. The rate of poverty among the albino population is high. Living in mostly rural areas and experiencing a lack of finances and law enforcement leaves adults, children and infants with albinism exposed. The sociological perspectives of albinism in Africa are commonly harmful. Depending on individual families' beliefs, children with albinism can be abandoned or sold. If fortunate to be spared from physical harm, they are often left poverty-stricken and malnourished. The hopeful news is that not all families follow this practice. Families often desperately cling on to their children despite albinism stigmas to protect them. In Malawi, Africa, Edna Cedric lost one of her sons to albino hunters, known as body hunters in her village. Despite living in severe poverty, she prepared herself and managed, with her neighbors, to fight off the hunters when they returned for her son's twin brother. Safety and Advocational Efforts for the Albino Community Amnesty International, a human rights organization, reported that Edna Cedric's son, and 19 other Malawians with albinism, were killed between 2014 and 2017. Amnesty International emphasizes that the total number of killings is much higher but often goes unreported by the local police. However, this kind of research has inspired groups across the globe, such as the United Nations' refugee organization, to address the brutalism. In recent years, relocation efforts have expanded. International organizations transport those living with albinism in Africa who experience brutal attacks to foreign hospitals, such as in Canada and the United Kingdom, at no cost. Medical practitioners treat albino hunter victims abroad to avoid further discrimination by local medical facilities. Additional care services such as transplants, physical therapy and surgery to repair skin damage are now accessible to victims. Furthermore, international efforts are moving to provide better treatment opportunities for those living with albinism in Africa. Because most of Africa's albino population falls below the poverty line, the majority cannot afford medical treatment. International outreach teams continue to provide crucial supplies in Africa at no cost. Simple items such as sunscreen, hats, sunglasses and eyeglasses prevent painful medical complications in the future. Training programs in African clinics educate practitioners about albinism's genetic condition to encourage the decrease of stigmas and malpractices. Highly encouraging is the ongoing collaboration between African countries. In recent years, East African governments have met together to create the Regional Action Plan on Albinism in Africa. The action plan for 2017 to 2021 includes holding accountable governments, medical facilities, law enforcement, communities and families to protect people living with albinism in Africa. By 2021, East African governments hope their destigmatizing campaign encourages the wide acceptance of albinos by faith organizations, public schools and communities. In Tanzania, affirmative action has gone as far as to accept a Tanzanian woman living with albinism as a member of the nation's parliament. Looking Ahead As national and global attention on albino mistreatment in Africa grows, communities across the continent will improve their societal perspectives on the genetic disorder, and authorities can bring violent groups to justice. Efforts from global organizations and African governments are crucial in leading societal and safety changes. Still, as vicious attacks and dismemberings occur day to day, increasing global awareness of these injustices is necessary to encourage protective growth for albinism in Africa. –Grace Elise Van Valkenburg Photo: Flickr #main-content .dfd-content-wrap {margin: 0px;} #main-content .dfd-content-wrap > article {padding: 0px;}@media only screen and (min-width: 1101px) {#layout.dfd-portfolio-loop > .row.full-width > .blog-section.no-sidebars,#layout.dfd-gallery-loop > .row.full-width > .blog-section.no-sidebars {padding: 0 0px;}#layout.dfd-portfolio-loop > .row.full-width > .blog-section.no-sidebars > #main-content > .dfd-content-wrap:first-child,#layout.dfd-gallery-loop > .row.full-width > .blog-section.no-sidebars > #main-content > .dfd-content-wrap:first-child {border-top: 0px solid transparent; border-bottom: 0px solid transparent;}#layout.dfd-portfolio-loop > .row.full-width #right-sidebar,#layout.dfd-gallery-loop > .row.full-width #right-sidebar {padding-top: 0px;padding-bottom: 0px;}#layout.dfd-portfolio-loop > .row.full-width > .blog-section.no-sidebars .sort-panel,#layout.dfd-gallery-loop > .row.full-width > .blog-section.no-sidebars .sort-panel {margin-left: -0px;margin-right: -0px;}}#layout .dfd-content-wrap.layout-side-image,#layout > .row.full-width .dfd-content-wrap.layout-side-image {margin-left: 0;margin-right: 0;}We use our own and third-party cookies to improve our services and to personalise and analyse your browsing. You can accept our cookies by clicking the OK button, change the settings or obtain more information in our cookies policy. + INFO Configuration OK Cookies policy "We are not animals to be hunted or sold" è il rapporto-denuncia di Amnesty International sulle violenze e discriminazioni contro le persone affette da albinismo in Malawi, pubblicato lo scorso giugno. Il Malawi è solo uno dei 23 paesi africani dove gli albini sono costretti a subire continue violazione dei loro diritti umani e a vivere in un clima di terrore e paura LE VIOLENZE CONTRO GLI "ZERUZERU" – L'albinismo è un'anomalia congenita ed ereditaria che consiste nella depigmentazione parziale o totale della pelle, dei peli e dei capelli, dell'iride e della coroide, da cui deriva una colorazione molto più chiara del normale o una totale decolorazione[1]. Secondo le stime ufficiali, l'Africa ospita il più alto tasso di persone affette da albinismo: a livello mondiale l'incidenza è 1 su 20.000 individui, mentre in Africa 1 su 17.000, anche se non esistono dati ufficiali in merito. Gli albini sono conosciuti come "figli della luna" per la loro pelle candida, ma sono chiamati anche in senso dispregiativo "zeruzeru" ossia figli del diavolo. In Malawi – che ospita tra i 7.000 e i 10.000 albini – dal novembre 2014 si è assistito a un drammatico aumento delle violenze nei loro confronti: sono 69 i casi ufficiali riportati, di cui almeno 18 omicidi e 5 persone scomparse. Le parti del corpo degli albini africani sono utilizzate per fabbricare amuleti contro il malocchio o per curare la sterilità, e le donne sono chiamate "machilitso", ossia cura: vengono violentate perché si crede che avere un rapporto sessuale con loro possa curare l'HIV. Embed from Getty Images Fig. 1 – Secondo l'organizzazione internazionale Amnesty International, il mese di aprile di quest'anno è stato il più cruento per gli attacchi contro le persone albine: neanche i bambini sono stati risparmiati Eppure la Costituzione del Malawi vieta qualsiasi forma di discriminazione per sesso, razza, religione, etnia, disabilità e sottolinea come tutte le persone devono essere uguali di fronte alla legge e protette. Purtroppo alla base degli attacchi e delle discriminazioni contro gli albini (a cui, ad esempio, è vietato l'accesso ai servizio pubblici, incluse cure mediche e istruzione) c'è una scarsa o totale conoscenza della patologia. IGNORANZA E VIOLENZA – L'ignoranza rappresenta un terreno fertile per il proliferare di leggende e credenze popolari che conducono all' emarginazione, esclusione sociale, alla stigmatizzazione della malattia. La maggioranza delle persone non sa che l'albinismo è una patologia genetica, ma crede che sia una punizione degli dei; molti altri credono che sia contagiosa. I bambini sviluppano questo senso di inferiorità ed esclusione fin dalla più tenera età quando vengono allontanati dalla comunità di origine e non possono frequentare la scuola. Le violenze verbali non sono meno gravi di quelle fisiche: i nominativi con cui vengono appellati tendono ulteriormente a creare un clima di sfiducia nei loro confronti e quasi a considerarli come esseri non umani. Inoltre, molti albini sviluppano il cancro alla pelle: non tutti possono permettersi di comprare la protezione solare e non tutti conoscono le complicazioni della malattia se non adeguatamente trattata. Embed from Getty Images Fig. 2 – Due ragazze ad Abidjan (Costa D'Avorio) mentre distribuiscono occhiali da sole e protezione solare durante una manifestazione di sensibilizzazione sull'albinismo. Nel banner alle loro spalle si può leggere "essere un albino non è una fatalità, noi abbiamo diritti e qualità" LA DENUNCIA DI AMNESTY INTERNATIONAL – I resti di una bambina di due anni, Whitney Chilumpha, sono stati ritrovati su una collina vicino la casa in cui viveva e in cui era stata rapita qualche giorno prima: 5 uomini, tra cui il padre, sono stati arrestati e sono sospettati di omicidio. Jenifer Namusyo, una donna di 30 anni, è stata ritrovata senza vita, con segni di pugnalate sulla schiena e sull'addome e mutilazioni. Davis Fletcher Machinjiri, diciassettenne, era stato rapito e portato in Mozambico, dove è stato ucciso: il corpo è stato trovato privo delle ossa. I corpi degli albini vengono smembrati poiché si crede che le varie parti portino fortuna e sono utilizzate per fabbricare amuleti molto costosi. Arti e organi vengono usati per pratiche rituali: secondo la magia nera africana, maggiore è il dolore provato dallo zeruzeru durante l'amputazione, maggiore sarà il potere sprigionato durante i rituali. Le ossa vengono vendute agli stregoni per produrre pozioni magiche e incantesimi, ma anche ai medici, nella convinzione che portino ricchezza e buona fortuna perché conterrebbero oro. Il Presidente Peter Mutharika e il governo malawiano hanno annunciato l'adozione di misure per fronteggiare la situazione e hanno diramato, nel marzo dello scorso anno, una nota di condanna degli attacchi esortando le agenzie di sicurezza ad arrestare i colpevoli e proteggere le persone a rischio di aggressione. Tuttavia la maggioranza delitti è rimasta irrisolta e le pene non sono proporzionali alla gravità dei crimini commessi; ciò fa sì che gli albini debbano vivere costantemente nel terrore anche perché spesso, soprattutto per questioni economiche, i responsabili di questi crimini si nascondono dentro le mura domestiche. Embed from Getty Images Fig. 3 – Il 13 giugno è la Giornata Internazionale dell'Albinismo: istituita dalle Nazioni Unite nel 2014, con l'obiettivo di aumentare la consapevolezza e la conoscenza di questa patologia e per eliminare le discriminazioni e le violenze contro le persone affette da albinismo IL MOVENTE ECONOMICO DIETRO LA STRAGE DEGLI ALBINI – Il Malawi è un paese povero, con il 53% della popolazione che vive al di sotto della soglia di povertà e ha un'economia dipendente dagli aiuti internazionali. Secondo un articolo apparso sul New York Times, le parti del corpo delle persone albine (orecchie, lingua, naso, genitali e arti) possono valere fino a 65.000 euro; la pelle è venduta a un prezzo che varia da 1.500 ai 7.000 euro, secondo l'età della vittima. Anche le Nazioni Unite hanno espresso la propria preoccupazione sulla situazione nel piccolo stato africano: Ikponwosa Ero, esperta indipendente delle Nazioni Unite per i diritti delle persone affette da albinismo, ha evidenziato una situazione drammatica «un'emergenza, una crisi inquietante nelle sue proporzioni» parlando di «pericolo di estinzione degli albini a causa del numero crescente di omicidi». La stessa Ero, affetta da albinismo, ha posto l'accento su come nemmeno nella morte gli albini possono riposare in pace, perché i loro resti vengono razziati nei cimiteri: a riguardo, le autorità del Malawi hanno registrato almeno 39 casi di riesumazione illegale. Dietro ci sarebbe un movente economico poiché la vendita delle parti del corpo delle persone affette da albinismo è un business spesso considerato molto redditizio anche dagli stessi familiari. Embed from Getty Images Fig. 4 – L'esperta Onu, Ikponwosa Ero, durante una conferenza stampa al termine della sua visita in Malawi lo scorso aprile: circa 10.000 albini rischiano l'estinzione a causa dell'incremento preoccupante del numero degli attacchi registrati contro di loro dal 2014 ad oggi OLTRE LE SUPERSTIZIONI – In Tanzania 1 persona su 1.400 è portatrice della patologia: un tasso d'incidenza molto alto rispetto alla media mondiale e africana, dovuto soprattutto al fattore della consanguineità; inoltre, molti albini costretti a vivere isolati ed emarginati si sposano tra di loro. Proprio in Tanzania, l'isola di Ukerewe è considerata un'oasi felice per gli albini, lontana dai pericoli della terraferma e dalla paura continua di attacchi: attualmente 75 albini vivono qui insieme alla popolazione locale. Non è ben chiaro perché questo pezzo di terra sia diventata un rifugio. Le teorie più accreditate rivelano che molti albini africani si siano spostati qui dopo essere stati allontanati dalla comunità di origine o che molti bambini siano stati abbandonati sull'isola dai genitori e poi cresciuti dalla gente del posto. Tornando sulla terraferma, invece, dal 2015, si sono verificati 160 atti di violenza contro gli albini, di 76 omicidi. In Tanzania, Burundi, Kenya, Repubblica Democratica del Congo, Mozambico, Sudafrica e Swaziland proliferano i mercati clandestini dove vengono vendute le parti del corpo mutilate agli albini. L'ex Presidente Jakaya Kikwete era intervenuto vietando qualsiasi pratica di stregoneria e arrestando centinaia di medici-stregoni. Una misura straordinaria, ma non totalmente efficace: dalle aree rurali il fenomeno si è diffuso nelle zone urbane. Particolarmente significativa la scelta delle Nazioni Unite di organizzare il Forum regionale sull'Albinismo lo scorso giugno a Dar es Salaam, capitale tanzanese. L'obiettivo del Forum era di trasmettere un messaggio molto importante: andare oltre le credenze popolari secondo cui le persone affette da albinismo sono figlie del diavolo o esseri immortali. Il razzismo contro gli albini potrà finire definendo una strategia di protezione integrata e comune contro le violenze e le discriminazioni. Purtroppo la situazione rimane preoccupante: i dati sulle violenze forniti dalle organizzazioni internazionali non mostrano un quadro completo della strage poiché molti casi non vengono segnalati e registrati dalle autorità. Gli attacchi sono diffusi nelle zone rurali tanto quanto in quelle urbane e, fino ad oggi, non sembra che i governi e le magistrature dei paesi coinvolti abbiano fatto abbastanza per proteggere gli albini africani anche perché spesso tra di loro si annidano le stesse credenze diffuse tra la popolazione. Irene Dell'Omo [box type="shadow" align="aligncenter" class="" width=""] Un chicco in più Definizione di albinismo qui. • Qui il report pubblicato da Amnesty International sulle violenze e discriminazioni contro le persone affette da albinismo. • Nel 2012 è uscito il documentario In the Shadow of the Sun, diretto da Harry Freeland, che racconta le condizioni di vita delle persone affette da albinismo in Africa: qui è possibile visualizzare il trailer del documentario. • Africa Bianca è il documentario radiofonico di due giovani giornalisti italiani, Barbara d'Amico e Fabio Lepore, che racconta la storia di Stéphane Ebongue, albino del Camerun scappato dal suo paese e dalle discriminazioni per il colore della sua pelle. [/box] Foto di copertina di Lars Plougmann Rilasciata su Flickr con licenza Attribution-ShareAlike License 28 February 2020 / EU- Logos 10 min Among the numerous problems that today afflict the African continent, it is possible to note that Albinism is particularly relevant and heavily affects the lives of many people, particularly in Sub-Saharan African countries. As shown in this article several measures have been taken in order to preserve the lives of people with Albinism; in order to better understand this situation, firstly we will focus on the analysis of albinism; secondly we will analyze the conditions of albinos in Africa, with a focus on Tanzania and finally we will verify the measures taken in favor of this category of people. What is Albinism? Albinism is a rare, non-contagious, genetic condition that limits the body's ability to process melanin, reducing or eliminating pigmentation in the skin, eyes and hair; it's a lifelong condition and does not cause intellectual disabilities. This condition occurs if both parents carry the albinism gene, in which case the probability of having an affected baby is 1 in 4 (25%); this possibility is the same in every pregnancy, having no relation to other births. Many children with Albinism have blue or brown eyes, occasionally the eyes might appear pink or reddish, because of very little color in the iris; because of these conditions and due of poor health and poor vision many children usually abandon schools. People with this condition are considered legally blind because their photoreceptors are unable to appropriately convert light into clear signals to the brain, leading to a condition called nystagmus, having also problems with reduced depth perception and with tracking an object with their eyes. Albinism occurs globally, in all gender, racial and ethnic groups affecting 1 person in 18,000; estimations of affected people as part of the local population vary from region to region, even though the highest rate is in Sub-Saharan Africa with an estimated 1 person in 1,400 people in Tanzania The condition of people with albinism in Africa Discriminations and attacks on people with albinism are particularly frequent in sub-Saharan Africa because of superstitious myths surrounding their nature. Albinos in these regions are often avoided by their communities and viewed as non-human spirits or ghosts; some believe that minerals contained within albino body parts bring wealth and luck, leading to dismember and kills of many albinos, including infants and children. "In some communities, erroneous beliefs and myths, heavily influenced by superstition, put the security and lives of persons with albinism at constant risk," states the United Nations website. "These beliefs and myths are centuries old and are present in cultural attitudes and practices around the world." Albino body parts such as teeth, bones, genitals, and thumbs have been used in rituals by traditional healers and witchdoctor, who say they promote health, riches and success; these body parts, consumed as "medicine" or carried around for good luck, are dried up, ground, and packaged for illegal trade. According to a 2013 UN Report, some believe albino body parts are more potent if the victims scream intensely during amputation.Moreover, there are superstitions in some parts of Africa that albino body parts bring power, wealth or sexual conquest, that having sex with a person with albinism cures HIV and AIDS. Furthermore, some believe that albinism is contagious and can be spread through touching, that their mothers were impregnated by a white man, that people with albinism have a low IQ and that they are housed by the ghosts of the European colonists. The Office of the UN High Commissioner for Human Rights stated in 2016 that albino hunters sell an entire human corpse for up to $75,000, while an arm or a leg could fetch about $2,000; related to that is also common that Albino graves are dug up and desecrated to procure body parts. There are very few health services in Africa focused on people with albinism, and many of those people cannot afford neither sunscreen nor protective clothing.Identified areas requiring both governmental and societal intervention include healthcare, advocacy and social awareness education, social inclusion, academic education, economic empowerment and socio-political protection from various forms of societal abuse and discrimination. The Tanzanian case As we have already seen, Tanzania has a high albinism rate (1 person in 1,400 people) that related to the high poverty of the country, (in which 80% of the population lives with less than $1.50 a day) makes life very difficult to people with Albinism, especially because of the cost of sunscreen, that is around $10, $15; furthermore, a very high number of Albinos murders have been recorded in this country, reaching 80 people since 2000, becoming one of the most dangerous countries for people suffering from this pathology. Following increased international inquiry at the end of the 2000s, Tanzania began to utilize resources to cope with traffickers and protect people with albinism; in order to do so since 2007 hundreds of children were removed from their families, sometimes without any consultation or consent, and placed in shelters where they were isolated from society; according to activists who spoke to Human Rights Watch, orders from the government to protect people with albinism were enforced by district commissioners, who oversee security in their respective districts being also responsible for their safety. The Tanzanian government also tackled impunity for ritual crimes, notably by investigating, arresting and prosecuting those who attack or sponsor attacks against people with albinism; in 2015, it announced a ban on witchdoctors, leading to over 200 suspects who were reportedly arrested by the authorities. After ten years from the begin of the wave of killings and attacks these appear to have decreased, because of Tanzania's stronger response to ritual crimes and attacks and protective measures, although these holding shelters are a temporary solution: "The shelters were emergency, temporary solutions. But 10 years is not temporary anymore," an activist for the rights of people with albinism told Human Rights Watch. Measures in favor of people with albinism European Parliament In 2017 the European parliament (EP) stated a resolution on situation of people with albinism in Malawi and other African countries: " The EP remains deeply concerned about the continuing systematic attacks and killings suffered by persons with albinism in Africa, in particular in Malawi, and strongly condemns any violence, discrimination and persecution directed at persons with albinism, as well as the trafficking of their body parts; Urges the Malawi's government, and the authorities of all countries affected, to take all necessary measures to ensure the effective protection of persons with albinism, as well as their families, and to eliminate all forms of discrimination against them; Recalls the Malawi's government of its obligation to protect the rights, dignity and physical integrity of their citizens in all circumstances and to put an end to the impunity enjoyed by their perpetrators by conducting the necessary investigations into these crimes and bringing those responsible to justice; Acknowledges the efforts made by the Malawi's authorities to tackle the phenomena; stresses however that progress is still lacking, in particular on improving the legal protection and action for victims, and ensuring adequate redress and rehabilitation mechanisms; Calls on the Malawi's authorities to adopt concrete strategies and policies to address the root causes of the phenomenon, notably by developing education and awareness-raising activities and campaigns on albinism; insists in this regard on the crucial role of local authorities and civil society organisations in promoting the rights of persons with albinism; Recalls that access to healthcare and education remains a great challenge for persons with albinism which needs to be tackled; calls for greater investment in creating adequate social, care and counselling structures for victims, in particular for women and children, as well as a better response to their medical and psychological needs; insists that policies should be put in place to facilitate their reintegration in their communities; Stresses the need to combat the marginalization of persons with albinism by ensuring their free and equal participation in society and the enjoyment of their civil and economic rights; Calls on the authorities of the countries affected, in cooperation with their international and regional partners, to commit to taking all necessary measures to prevent and tackle the illegal trade of albinos' body parts, track down traffickers and dismantle their networks; Recalls that violence against albinos is often of a cross-border nature and insists on the need to strengthen regional cooperation on the matter; welcomes, therefore, all initiatives taken at the regional and international levels to fight violence against persons with albinism and in particular the recent adoption of the Regional Action Plan 2017-2021, jointly by the African Union and the UN which is a positive and concrete signal of commitment by African leaders; calls for its immediate and effective implementation; Calls on the EU to closely monitor the human rights situation of PWA in Africa, particularly through regular reporting by its delegations in the countries most affected; Reiterates its full support to the work of the Independent Expert on the human rights of people with albinism; Calls on the EU and its Member States to continue to support the countries affected in fighting violence on grounds of albinism and improving the social integration of persons with albinism, notably through its development programmes and political dialogue and by sharing best practices and providing the necessary technical assistance; Instructs its President to forward this resolution to the Council, the Commission, Vice-President of the Commission / High Representative of the Union for Foreign Affairs and Security Policy, the African Union and the Secretary-General of the United Nations". NGOs As stated by international human rights law, children with albinism have the right to live in a family environment. This is why local NGOs are making efforts to reunite children and families; among these Advantage Africa in the Busoga sub-region of Uganda is supporting more than 1,000 people with albinism to improve all aspects of their lives, helping children and adults with albinism to feel safe, accepted and included within their schools and communities. In doing so these organizations operates improving livelihoods, access to hats, high-factor sun screen, dermatology, vision and other health care services; moreover, it has introduced cryosurgery, a product that use liquid nitrogen to remove pre-cancerous lesions from the skin of people with albinism. Tulime Onlus Another important activity conducted by NGO is advocate in favor of people with Albinism, informing common people about this disease, thus eliminating prejudices and beliefs and conducting awareness-raising lessons in schools, achieving greater understanding among children, as Tulime Onlus is currently doing in the Iringa region in Tanzania. United Nations The United Nations (UN) has stressed the extreme discrimination faced by people with albinism; in 2013 the UN Human Rights Council called for the prevention of attacks and discrimination against PWA and in December 2014, the UN General Assembly adopted a resolution declaring the 13th of June each year as International Albinism Awareness Day. Moreover, as person with albinism are identified as disabled people they have guaranteed human rights as set out by the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD); these rights include a right to life, adequate standards of living and social protection, equality and non-discrimination, freedom from exploitation, violence and abuse, and a right to education, health, work and employment. Conclusion Despite the huge work that is currently carried on in Africa, especially from NGOs, people with albinism are still exposed to different risks and threats from both their relatives and community; in countering this situation is important to consider the important role played by several international organization, which play an important part in sensitizing and informing people, although old beliefs and rites are hardly abandoned by the poorest and less educated people, who think they can solve their problems by turning to sorcerers and wizards. In order to cope to this situation, the government's response should be guided on one hand by the best interests of the children involved, balancing the child's protection and safety with the preservation of the family environment and the pleasure of other rights and on the other hand on the education of the population of the poorest countries of Sub-Saharan Africa through the development of new educational policies at national level, a policy which is unfortunately often not pursued by governments. Bianco Nicola As a library, NLM provides access to scientific literature. Inclusion in an NLM database does not imply endorsement of, or agreement with, the contents by NLM or the National Institutes of Health. Learn more: PMC Disclaimer | PMC Copyright Notice BMC Int Health Hum Rights. 2018 Jan 12;18:2. doi: 10.1186/s12914-018-0144-8 Albinism is an inherited condition with a relatively high prevalence in populations throughout sub-Saharan Africa. People with oculocutaneous albinism have little or no pigment in their hair, skin and eyes; thus they are visually impaired and extremely sensitive to the damaging effect of the sun on their skin. Aside from the health implications of oculocutaneous albinism, there are also significant sociocultural risks. The impacts of albinism are particularly serious in areas that associate albinism with legend and folklore, leading to stigmatisation and discrimination. In regions of Africa those with albinism may be assaulted and sometimes killed for their body parts for use in witchcraft-related rites or to make 'lucky' charms. There is a dearth of research on the psychosocial aspects of albinism and particularly on how albinism impacts on the everyday lives of people with albinism. There is a growing recognition and acceptance in Africa that people with albinism should be considered disabled. Thomas's social-relational model of disability proposes it is essential to understand both the socio-structural barriers and restrictions that exclude disabled people (barriers to doing); and the social processes and practices which can negatively affect their psycho-emotional wellbeing (barriers to being). In this article, we combine a social model of disability with discussion on human rights to address the lacuna surrounding the psychosocial and daily experiences of people with albinism. Through using this combined framework we conclude that the rights of people with albinism in some regions of Africa are not being enacted. Our debate highlights the need to develop a holistic concept of rights for children and young people with albinism which sees human rights as indivisible. We illuminate some of the specific ways in which the lives of children with albinism could be improved by addressing 'barriers to being' and 'barriers to doing', at the heart of which requires a shift in attitude and action to address discrimination.Keywords: Children with albinism, People with albinism, Barriers, Children's rights, Disability, Human rights, Africa To date there is a paucity of research on the psychosocial aspects of albinism [1] and on the experiences of people with albinism (PWA). Significantly, the experiences and perspectives of children with albinism are underexplored and little is known about the psychosocial issues facing this group. Limited understanding of their lives in an African context and a lack of attention given to the particular needs of this group of children means that interventions to better support empower and protect them remain elusive. Inspired by Thomas' notions of 'barriers to being' and 'barriergs to doing' [2] and underpinned by a human rights approach, our innovative lens seeks to explore the challenges that PWA and their families face in some regions of sub-Saharan Africa, especially in countries where discrimination against PWA is common. Our integrated framework incorporates sensitive approaches to social protection, useful in countries of low economic resource [3]. It can keep us alert to the barriers 'to being' and 'to doing' that might exacerbate the vulnerability of PWA. Albinism is a genetic condition caused by a deficit in production of the pigment melanin. It affects populations across the globe regardless of gender or ethnicity although frequencies vary. There are different types of albinism, but the most common and visible is oculocutaneous albinism. There are few detailed epidemiological studies, but the prevalence of albinism has been approximated at around 1 in 2000–5000 throughout sub-Saharan Africa [4, 5]. Data on the prevalence of albinism amongst school children in Zimbabwe and South Africa estimates a prevalence rate in the region of 1 in 2000 to 4000 [6, 7]. Demographic data from 2011 in Namibia revealed the highest national prevalence reported in Africa to date at 1 in 1755, compared with 1 in 2673 in the 2012 census in Tanzania [8]. Children in African communities born with oculocutaneous albinism lack pigment in their skin, hair and eyes due to inherited recessive mutations in one gene. This has serious implications for their physical health and wellbeing. Lack of skin pigmentation means that they are very sensitive to the damaging effects of the sun. Harsh sunlight causes skin cancers and exacerbates eye conditions [9]. Albinism results in poor vision, with involuntary nystagmus, photophobia, poor depth perception, strabismus, poor visual acuity and refractive errors [7]. In one study 85% of children with albinism in South Africa were found to have less than 30% vision, even with best optical correction [8]. If not understood or managed incorrectly, albinism can have deleterious health and social impacts on the lives of children with the condition. Aside from the physical consequences of oculocutaneous albinism, there are also significant sociocultural risks. In Africa the lack of pigmentation makes the visible appearance of those with the condition markedly different to their dark skinned families and communities. The impacts of albinism are particularly acute in regions of the world where myths and superstitions surrounding the condition can lead to stigmatisation, discrimination and additional health issues such as cancers due to a lack of adequate sun protection and appropriate treatment of early pre-cancerous lesions. In the last 10 years there have been cases of violent assault and murder as PWA are targeted for their body parts for use in witchcraft-related rituals to make charms believed erroneously to bring easy wealth and good fortune [10]. Disability specifically refers to negative interactions between people with impairments and the internal and external environment [11]: Disability is the umbrella term for impairments, activity limitations and participation restrictions, referring to the negative aspects of the interaction between an individual (with a health condition) and that individual's contextual factors (environmental and personal factors). There is a growing recognition and acceptance in Africa that PWA should be recognised as disabled [12], although on an individual level people may not necessarily accept or adopt such a label. In a recent study assessing prison life of disabled people in Ghana, albinism was named specifically as one of six categories of disability [13]. As disabled people, PWA are afforded human rights as set out by the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) [14]. These rights include a right to life, adequate standards of living and social protection, equality and non-discrimination, freedom from exploitation, violence and abuse, and a right to education, health, work and employment. For a number of years the United Nations (UN) has underlined the extreme discrimination faced by people with albinism. In 2013 the UN Human Rights Council called for the prevention of attacks and discrimination against PWA [10] and in December 2014, the UN General Assembly adopted a resolution proclaiming the 13th of June each year as International Albinism Awareness Day [15]. Moreover, in March 2015 the Council created the mandate of Independent Expert on the enjoyment of human rights by PWA in response to groups advocating for PWA to be seen as a specific group with particular needs requiring attention [16]. More recently (2017) the International Bar Association proposed universal standards for the protection and promotion of rights for people with albinism [17]. Within the African context children with albinism not only have rights as disabled people under the UNCRPD; they are also afforded rights under the United Nations Convention on the Rights of the Child (UNCRC) [18] which has been signed and ratified across Africa. Additionally, the 1999 African Charter on the Rights and Welfare of the Child was created to provide additional rights to protection and outlines the rights that African countries must ensure for their child population [19]. It is the main instrument of the African human rights system for promoting and protecting child rights, complementing the UNCRC in addressing issues of discrimination, empowerment and protection. Despite such legislative protection of rights, it is only recently that a detailed examination of the rights of children with albinism has been undertaken [17]. The social model of disability makes a distinction between impairment, the lost or limited functioning experienced by an individual, and disability, the barriers that people with impairments face because of the way societies are structured [20]. Barriers may be social, cultural, material, physical or attitudinal and they exclude people with impairments from mainstream life. As the evidence illustrates these barriers are frequent aspects of the everyday lives of PWA in Africa. In the further development of the social model of disability, Thomas' work on social relational understandings of disability also recognises the significance of impairment effects, meaning the day-to-day impact of living with particular conditions or impairments [2]. In the case of children with albinism, impairment effects include poor vision and potential skin damage due to the effects of the sun. Thomas argues that people may use such impairment effects to exploit a person, an act of disablism. Thomas argued for a two-pronged approach to understanding and tackling disablism: understanding the socio-structural barriers and restrictions that exclude disabled people ('barriers to doing'); and understanding the social processes and practices which can negatively affect the psycho-emotional wellbeing of people with impairments ('barriers to being'). This model has been used with effect in the study of disabled children [21]. Although social models of disability are predominately used in Western definitions of disability, Brocco argues that the definition of being a disabled person may constitute a way for PWA to find alternative and more suitable epistemologies for albinism than some of the dominant negative discourses [22]. He argues that adopting a disability definition may help PWA explain to others why they cannot do certain activities such as working outdoors – 'impairment effects'. In our view, the most important contribution is that it gives PWA the same recognition for financial or other support afforded other disabled people. There is evidence to show that social processes and practices severely affect children with albinism and as such they face significant 'barriers to being', most seriously, their right to life and protection and the right to freedom from discrimination. Although there are laws in Africa and beyond protecting PWA, these need to be implemented effectively [23]. International responses are criticised for being limited to little more than political rhetoric and only the media and NGOs are thought to have had any traction in raising awareness and conducting advocacy work [24]. In a recent study in the lake region of Tanzania respondents did praise the government's awareness campaigns though, which are viewed as the main reason for an improvement in attitudes towards PWA (personal communication Lund). In the 2 years following 2008 when the Tanzanian government declared it a capital crime to kill people with albinism, more than 170 people were arrested in that country. However very few were prosecuted, with courts citing a lack of funds for litigation as the reason [25]. The situation seems little changed since that study [17]. In response to the extreme violence against children with albinism, the Tanzanian government implemented a policy of moving children with albinism from their family homes into special schools and camps in order to protect them [24]. It is argued that while emergency response might have increased security, concerns were raised about overcrowding, inadequate facilities and support, incidents of child abuse and family members abandoning their children in the facilities [24]. The impact of this form of segregation on family life has received less attention and even less so the impact on the wellbeing of the children. Alongside a right to protection of life, PWA also have the right to health protection, including access to skin and eye health services and provision of skin protection materials such as protective clothing and sunscreens. The high risk of developing skin cancer makes it essential that children with albinism are taught about and are enabled to implement effective sun protection from an early age. However, in Lund's study in Zimbabwe [26], only 23% of her sample of children had ever had their skin examined by a health professional and this was often only when they were babies. In terms of other health needs, less than half in this sample (46%) had been to a hospital or private optician for an eye test and only 27% had prescription glasses, 5% of who felt that they did not improve their eyesight. Similarly, in a sample of 38 children in a rural special school for visually impaired children in South Africa the 'sun protection' used by the children was often in the form of inexpensive aqueous creams with no sun protection [7]. Even where these did provide some protection it was of an inadequately low SPF value for oculocutaneous albinism [7]. Lund reports on the persistent skin and eye problems of children with albinism in a study in Zimbabwe, highlighting the lack of suitable health care facilities and social care support, with many families relying solely on support from within their families [27]. It is important to note that negative attitudes towards PWA are not unique to Africa. For example, Wan [28] reports on the disablism experienced by PWA predominately in North America and their strategies to resistance. Moreover attitudes on the African continent vary significantly and appear slightly more positive in West Africa in that it is not as threatening for PWA living there as in parts of Southern Africa (personal communication PL and J Epelle (CEO) The Albino Association of Nigeria and UN Albinism Champion). Myths and superstitions, fuelled by a lack of understanding surrounding albinism and the visible difference in the appearance of PWA can lead to stigmatisation, rejection, a lack of acceptance, perceptions of difference and limited social integration [1, 22, 25]. Their visible difference is so stark that they are in effect viewed as white people within a black community. Bucaro [25] points out some of the cultural superstitions in Tanzania whereby the health issues faced by PWA are seen to be a result of a curse, or they are seen as 'omens of disaster'. Furthermore Brocco [22] highlights the negative labels and terminology used to describe and define PWA in Africa. Mothers of children with albinism are often blamed for their child's condition, accused of infidelity with white people, carriers or spirits [29]. Thus many children with albinism are raised without the support of both parents, creating financial difficulties and an inability to afford health care or education for their child [25]. The efforts of many NGOs in Africa aim to offer this support. Other authors have explored the implications of both old and new myths about albinism on personal identity and social acceptance [29]. Over half of the pupils in a sample of schoolchildren in Zimbabwe did not know why their skin was pale – other common misconceptions being that they thought they had the top (black) layer of skin missing [27]. If well informed, teachers can be an important, effective route for dissemination of information about genetics and health care, especially as they are such highly respected members of the community [27]. Recent anthropological research has critiqued the media for their simplistic approach of blaming traditional superstitions for the killings of PWA, identifying that contract killers are fulfilling a market demand for body parts for use as charms thought to bring wealth and good fortune [24]. There are strong arguments that it is poverty that drives the violence towards PWA [25] and this is specifically acknowledged by the United Nations as a key contributor to witchcraft related violence [26]. It is possible to make a direct link to the boom in mining and rapid social change and inequalities in Tanzanian society [24, 30, 31] and though poverty in and of itself does not cause violence; in terms of PWA it seems to be a significant risk factor. Media reports of violence against people with albinism have mostly focused on identifying and punishing the perpetrators, although there are articles focused on awareness raising and political activism [24]. Burke et al.'s content analysis of media reports illuminate how some of the strategies aiming to prevent abuse or violence are criticised and debated, highlighting the complexities involved in protecting and promoting competing rights [24]. The profound effects of this violence, on PWA as well as on the wider community, are also documented regularly in the media, illustrating how family members are forced to escort their children to school and to other areas of the community. There are accounts of parents hiding their children at home, seeking asylum in police stations or moving to safer parts of the country. Some families report sending their children away to boarding schools, camps or relations in safer areas [24]. Such media attention has also raised awareness of the need to address the challenges facing PWA, including stigma and the lack of access to education and health services [24]. Thomas emphasizes the importance of understanding the psychosocial effects of disablism [2]. Although there is a paucity of evidence on this aspect, a qualitative study conducted with 15 adults with albinism in South Africa highlighted the negative effects the disablist external environment can have on self-image and on their sense of belonging at home and within the wider community [1]. Previous studies have also identified that prejudice and stigma are a major challenge faced by most PWA [32, 33]. A sample of children with albinism in Zimbabwe reported problems they encountered around children avoiding, antagonising and indeed fearing them [28]. Further, the development of self-esteem through group and team activities taking place in outside spaces is being denied to this group [7]. Individual testimonials provide first-hand accounts of these difficulties. The first Member of Parliament with albinism to be appointed in Tanzania, Ms. Kway-Geer, described her life as a schoolchild: When I was at primary school, people used to laugh at me, tease me - some didn't even like to touch me, saying that if they touched me they would get this colour. People used to abuse me on the road when I took the buses to school. They would run after me - crowds of kids following me - shouting 'zeru, zeru' (derogatory term for someone with albinism) [34]. Both children's rights and those of disabled people are compromised by the 'barriers to being' faced by children and adults with albinism, summarised in Table 1. Evidence of Barriers to Being & the Unenacted Rights of People with Albinism (relevant Article in parentheses) Barriers to Being Rights afforded under the UNCRC (1989) Rights afforded under the UNCRPD (2006) Exposure to/fear of violent assault, abduction & murder ➢ Right to life, survive & develop (6)➢ Protection from violence, abuse & neglect (19).➢ Governments must protect children from being abducted, sold or moved illegally for the purpose of exploitation (35).➢ Children who have experienced abuses must receive support to help them recover (39). ➢ Right to live (10).➢ Governments must take all necessary measures to ensure the protection & safety of people with disabilities in situations of risk (11).➢ Right to freedom from exploitation, violence & abuse (16). Effects of discrimination & stigmatisation ➢ Right to live full & decent lives with dignity & as far as possible, independence & to play an active role in their community (23). ➢ Right to equality & non-discrimination & equal protection & benefit of the law (5).➢ Governments must raise awareness of the capabilities of disabled people & challenge discrimination & prejudice (8).➢ Right to live independently in & be included in the community 19). Effects of segregation from family &/or community & lack of freedom of movement ➢ If a child is place away from home for the purposes of protection they have the right to regular review of their care & circumstances (25). ➢ Right to access all aspects of society on an equal basis (9).Right to liberty & security of person (14). Impact on family life & friendships ➢ Children must not be separated from parents against their will unless it is in their best interests (9). ➢ Children with disabilities have equal rights to family life and to prevent concealment, abandonment, neglect and segregation (23) Inadequate health protection & health support ➢ Governments must provide good quality health care & education on health & wellbeing (22). ➢ Right to highest attainable standard of health without discrimination (25). Inadequate health information on the causes & effects of albinism ➢ Right to reliable information from a range of sources (17). Lack of access to justice & few convictions of perpetrators of violence ➢ People with disabilities should have effective access to justice (13). Lack of voice on issues affecting children with albinism ➢ Right to express their views, feelings & wishes in all matters affecting them & to have their views considered & taken seriously (12). ➢ Right to express their views on all matters affecting them (7).➢ Right to express themselves & access information (21). Evidence suggests that PWA in parts of Africa face many 'barriers to doing', structural and physical barriers that prevent them from being included fully in society or having the same opportunities as their non-disabled peers. This is enacted at a personal level (the right to a fulfilling life), at a relational level and at a social level (the right to education). The right to live independently may also be expressed as the right to live a fulfilling life and in the African context, this involves earning a living and supporting the family. Unpublished and anecdotal accounts attest to the challenges faced by PWA as they transition from childhood into adulthood and the potential barriers that this group might face as young adults. Clearly, the impact of childhood experiences has the potential to affect this transition and there is clear evidence that discrimination continues into adult life. Lund's study of adults with albinism in Zimbabwe highlighted the difficulties encountered in obtaining employment [27]. Baker and colleagues stress the prejudices people with albinism face from employers, emphasising the importance of employment for this group, both economically and for social acceptance [30]. Kiprono et al.'s study on quality of life for PWA in Tanzania recorded that half of his sample (n = 128) were unemployed and half of these had experienced discrimination by employers [35]. Those who were employed reported facing many challenges in their work, including sun exposure and vision needs, with 10% describing discrimination in the work place. Some studies have accentuated the difficulties some PWA face in developing relationships because of discrimination and stigma [28], especially the importance of acceptance by a partner's family and friends [27]. The social isolation of children with albinism can be confounded by the barriers they face to being able to play outside with other children and to take part in outdoor activities at school whilst remaining safe from the damaging effects of the sun. As an illustration of prejudice, one study of students in a South African university reported that six out of 10 students who did not have albinism stated that they would not date a person with albinism [36]. In Kiprono et al.'s Tanzanian study, of people who were eligible for marriage over half were single and of those who were married, half reported problems with their partners because of their albinism [35]. The colour of their skin was also cited as a significant cause of divorce or separation. It should be noted that being unmarried is more unusual and stigmatising in many African countries than it is in the global north. There are mixed policies on the education of children with albinism in Africa, meaning children experience a range of educational experiences. Sometimes they are educated in specialist schools for visually impaired children, although there is an increasing move to adopt inclusive education [12]. However, in some families and communities, children with albinism are not seen as 'worth educating' [37] as they are not considered able to contribute in society in the same way as others. An inclusive education study identified gender inequalities in the education of children with albinism in Malawi [37]. Despite albinism affecting boys and girls equally, twice as many boys as girls were attending Resource Centres offering specialist support for their low vision, indicating a gender bias in accessing this service. This study also revealed how parents feared sending their child to school, concerned for their safety while walking to school and lack confidence in teachers' abilities to keep them safe. Children with albinism have a right to education, thus attention needs to be given to ensuring that their needs are met within mainstream settings. This can sometimes mean only minor adaptions to classroom layouts, such as access to visual aids, but perhaps more fundamentally requires a change in attitudes amongst teaching staff and other pupils. A study at a special school for children with albinism in rural South Africa identified that although the school had access to magnifiers and low vision devices, these were only used in specific lessons such as map reading [7]. In Zimbabwe and parts of Zambia children with albinism attend mainstream schools where inclusion can be challenging. Teachers can fear teaching a child with albinism [38] and a lack of education and correct information about the condition in the local community inevitably increases the probability of teachers drawing on local myths in their approach to children with albinism [30]. Access to appropriate educational support, including teachers with the knowledge of how to assist children with albinism has been recognized as important in enhancing the self-esteem of these children, promoting their personal development and growth and creating a sense of belonging [1]. Both children's rights and those of disabled people are compromised by the 'barriers to doing' faced by children and adults with albinism, summarised in Table 2. Barriers to Doing & the Unenacted Rights of People with Albinism (relevant article in parentheses) Barriers To Doing Rights afforded under the UNCRC (1989) Rights afforded under the UNCRPD (2006) Reduced educational opportunities due to fear & discrimination ➢ Right to an education (28). ➢ Right to an inclusive education without discrimination (24). Lack of employment opportunities & discrimination by employers ➢ Right to work, including the right to work in an environment that is inclusive & accessible (27). Living an independent, fulfilling life ➢ Right to live full & decent lives with dignity & as far as possible, independence & to play an active role in their community (23). ➢ Right to take part in cultural life, recreation, leisure & sport (30). Segregation from community ➢ Right to relax, play & take part in cultural activities (31). ➢ Countries must make appropriate measures to enable people with disabilities to develop, attain & maintain maximum ability, independence & participation through provision of services (26). Discrimination in developing relationships/friendships ➢ Right to marry & to found a family. Lack of voice & empowerment ➢ Governments must actively work to make sure children & adults know about their rights (42). ➢ Governments must raise awareness of the rights of people with disabilities (8). As discussed so far, evidence has demonstrated that PWA in Africa face significant barriers both to being and to doing (see Tables 1 and 2), but there is less evidence on how these barriers should be overcome. Within a rights framework it can be argued that many of the rights of the child are not being enacted. Burke et al. [24] contend that the government response in Tanzania to the killing of people with albinism, including increased segregation of children with albinism, has resulted in trade-offs between competing rights, potentially causing further harm to victims and families. PWA face real complexity when the right to life and protection can simultaneously lead to loss of other freedoms and rights, such as a family life, engagement in the community or freedom of movement. It has been argued that the concept of vulnerability is at odds with a rights framework for PWA [39]. For example, the notion of vulnerability can leverage resources and action to promote protection and ensure PWA's right to social justice. On the other hand it can also be used to justify social control, which has at times resulted in the placing of children with albinism in secure schools and other institutions. Burke et al. [24] argue that while residential care may sometimes be a life-saving intervention, it cannot be a sustainable solution due to the negative consequences on families and on the social and emotional development of children. Unless interventions are based on a holistic conception of human rights as indivisible, children with albinism will remain socially excluded and segregated from their families and communities [24]. The UNCRPD [13] contains specific obligations on governments to challenge the stereotypes and prejudices experienced by PWA, with what seems to be a patchy response. Segregation, for whatever reason, contravenes fundamental rights to leading independent, fulfilling lives, accessing education and work and developing relationships within local communities. In addition, the voices of children with albinism on this subject have not been heard, despite their right to express their views and choices on matters affecting them. Whilst there is an argument that this might apply to most African children, those with albinism are afforded no voice at all at this time. Clearly significant challenges remain in protecting and promoting the rights of PWA. The evidence suggests that a starting point has to be in ensuring the identification, conviction and punishment of perpetrators of violence towards this group of people and in addressing discrimination and prejudice. Further work is also needed to promote awareness and understanding of albinism and to secure the multitude of other rights being denied to PWA and their families. A qualitative study with 15 participants (aged 18–48 years) in South Africa illustrated that people with albinism want to eradicate myths and misconceptions, lobby for their rights and be treated with dignity and equality [1]. The study suggested that the role of albinism advocacy groups was valued by those accessing them. In particular, the provision of services such as counselling and raising awareness had enhanced self-esteem and a sense of empowerment. Advocacy was also seen as crucial in influencing the media, NGOs and governments. Employment was perhaps not surprisingly also found to be associated with higher levels of self-esteem [1]. Empowering children and young people and advocating for their rights requires financial investment and political will from those in local and national positions of power. Accessing complaints, investigating and reporting mechanisms under the African Children’s Charter and the CRC could be, and has to some extent been, utilised as a potential avenue by advocacy groups to pressure governments and organisations to take human rights violations seriously and improve the human rights of children with albinism. If national legal systems do not provide a remedy for human rights violations, alternatives such as the Optional Protocol to the Convention on the Rights of the Child on a communications procedure (OP3 CRC) which came into force on 14 April 2014 [40], could also provide children themselves with the opportunity to access justice at an international level. However, children will only be able to use this complaints procedure if their States ratify OP3 CRC, and this is yet to happen across most of Africa. The requirement for countries to fulfil their obligations under the UNCRC and UNCRPD should be a stimulus for action, enacted in legislative measures, implementation plans and full evaluation and measurement of impact of actions [17]. Despite such obligations, politically active disabled people call repeatedly for the strengthening of human rights frameworks which recognise and address the barriers they face [41]. There is a severe lack of rigorous empirical research into understanding the lives of PWA, especially from their perspective and within a social-relational model of disability. Their voice concerning how their rights are being enacted or denied, the barriers they face and what might better support, empower and protect them has to date been denied. The limited available evidence on living with albinism has been predominately adult focused, with little attention being given to the unique experiences of children. Exploring what is known about children with albinism within an integrated disability and rights lens helps to identify and frame the barriers faced by this group and suggest possible ways to overcome them. The CRC and CRPD together provide a framework for children with albinism and their advocates to call governments and others accountable when their rights are not enacted and thus create, or permit the continuation of, barriers to ‘being’ and ‘doing’. Together these conventions should provide multiple avenues to facilitate the protection and rights of children with albinism. In addition, our debate has illuminated the need to develop and enact a holistic concept of rights for PWA, which sees human rights as indivisible. Although little attention has been given to the issue, the evidence highlights that in trying to meet the fundamentally critical right to life and protection, other important rights are being denied. This debate has emphasized specific ways in which the lives of PWA could be improved by addressing the ‘barriers to being’ and ‘barriers to doing’. At its heart this requires both a shift in attitude and action to address discrimination among this group of people.

We are grateful to Luisa Tarczynski-Bowles and Claire Pillinger at Coventry University who were the research assistants on the FIRAH project and assisted with the initial literature review. A major part of the literature review that informed this debate was funded by the International Foundation of Applied Disability Research (FIRAH) for a study led by PL at Coventry University. The University of Birmingham contributed the publication costs.

All data supporting the debate is contained within the manuscript. Any additional information can be shared upon request. NGO Non-governmental organization PWA People with albinism UNCRC United Nations Convention on the Rights of the Child UNCRPD United Nations Convention on the Rights of Persons with Disabilities WHO World Health Organization PL and AF conceived the debate, participated in its design and contributed to writing the manuscript. JT and CBJ developed the themes and structure and contributed to the design and writing of the manuscript. All authors contributed to the integrated theoretical framework. All authors read and approved the final manuscript. Not applicable Not applicable The authors declare they have no competing interests.

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Oculocutaneous albinism is an autosomal recessive disorder characterized by a lack of pigment in the hair, skin, and eyes. Albinism is caused by defective or absent tyrosinase, an enzyme necessary for melanogenesis. Although rare in the western world, albinism is quite common in sub-Saharan Africa, likely as a result of consanguinity. Albinism has long been associated with stigma and superstitions, such as the belief that a white man impregnated the mother or that the child is the ghost of a European colonist. Recently, a notion has emerged that albino body parts are good-luck charms or possess magical powers. These body parts may be sold for as much as $75,000 on the black market. As a result there have been over 100 albino murders in Tanzania, Burundi, and other parts of Africa in the past decade, which is now beginning to garner international attention and thus prompting novel legislation. To ameliorate the plight of individuals with albinism in Africa, a coordinated effort must be organized, involving medical professionals (dermatologists, ophthalmologists, oncologists), public health advocates and educators, social workers, human rights and antidiscrimination activists, law-enforcement agencies, and governmental support groups. The main issues that should be addressed include skin cancer prevention education, stigma and discrimination denouncement, and swift prosecution of albino hunters and their sponsors.