

# We Are Human, Just Like You: Albinism in Malawi – Implications for Security

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## Abstract

The plight of people with albinism in Malawi has received little attention, despite evidence of increasing attacks on people with albinism for their body parts for use in rituals in recent years. While a recent spate of attacks on people with albinism in late 2020 and early 2021 has drawn the attention of international organizations, relative inaction on the part of the authorities places the security of people with albinism in Malawi firmly in their own hands, and those of their families and communities. This article draws on the findings of participatory research undertaken between 2015 and 2019 to explore context-specific knowledge about the security of people with albinism in Malawi and to reveal perceptions of what makes people with albinism secure or insecure. It traces the roots of these attacks in the beliefs associated with albinism and other disabilities, the various threats to people with albinism in Malawi, and responses put in place at different levels of society to ensure their personal security. Framed in relation to critical work in the field of human security, our findings underscore the importance of changing societal attitudes and developing a coordinated collaborative response to bring about effective and lasting change.

## Keywords:

Albinism; Human Security; Beliefs; Malawi

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## Introduction

In response to seven attacks on people with albinism (PWA) in Malawi in just four months between November 2020 and February 2021, Amnesty International published a press release highlighting a resurgence of killings and abductions of PWA in Malawi as ‘a dangerous escalation’ (Amnesty International, 2021). The report cites Muleya Mwananyanda, Amnesty International’s Deputy Director for Southern Africa, who remarks that ‘People with albinism are simply not safe in Malawi, whether in their homes or on the street’ (Amnesty International, 2021). This follows the organization’s earlier report of 2016, which acknowledged the threat to PWA in Malawi. The report focused on the lived experiences of PWA in the context of what its authors term ‘superstition-driven attacks’ against them and the corresponding government failure to protect their right to life and to guarantee their right to security of person. The report’s authors comment that:

Human rights violations and abuses against people with albinism in Malawi range from widespread societal discrimination that is evident in verbal abuse in public, exclusion from access to public services, including education and health, through to extreme forms of violence that include killings, abductions, mutilations and infanticide. Even after a person with albinism has died, their graves are at risk of exhumation by individuals or gangs attempting to obtain body parts to sell. (Amnesty International, 2016)

The hair, bones and genitals of PWA are said to possess distinct powers. Alleged to bring wealth or success, they are often dried and ground, put into a package to be carried, to be secreted in boats, businesses, homes or clothing, or scattered in the sea (UNHRC, 2017). PWA live in fear for their lives and are forced to take measures to protect themselves or to rely on their families and communities for their safety. Some have been forced to flee their homes or have been relocated for their own protection, while others have been obliged to seek exile to avoid attack. While data is scarce, the evidence that has been gathered by the non-governmental organisation, Under the Same Sun and by UN Human Rights Council demonstrates

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an escalation in attacks reported in Malawi in recent years. Under the Same Sun records 56 reports of violence against PWA, including 18 killings, 25 survivors, 5 missing persons and 7 grave robberies in their report of March 2021, while the UNHRC records over 150 cases of killings, attacks and other human rights violations against PWA reported in Malawi since 2014 (UNHRC 2019). The UN Independent Expert for the enjoyment of human rights by persons with albinism, Ikponwosa Ero, signals in her report to the Human Rights Council in January 2019 that a greater number of attacks against persons with albinism take place than are formally recorded:

According to information received from civil society organizations in Zambia most of the attacks and violations against persons with albinism are perpetrated by friends and close relatives and are rarely reported. Incidents of non-reporting are also due to fear related to witchcraft beliefs. In Southern Africa, attacks often go unreported and undocumented due to the code of silence surrounding such crimes. Underreporting has also been attributed to the location of such attacks. In instances where attacks occur in remote settings that are a considerable distance away from law enforcement offices, they are likely to remain unreported; it often takes a long time for the public to learn about the violations, if they ever do. (A/HRC/40/62)

Oculocutaneous albinism is a recessive genetic condition that causes a lack of pigmentation in the hair, skin and eyes, and is the most prevalent type of albinism found in sub-Saharan Africa. The absence of melanin in the skin means that PWA are vulnerable to sun damage and face an increased risk of developing skin cancer, while the absence of pigment in the eyes causes varying degrees of visual impairment. As Anita Franklin *et al.* remark, ‘There is a growing recognition and acceptance in Africa that people with albinism [PWA] should be recognised as disabled, although on an individual level people may not necessarily accept or adopt such a label’ (2018, p.2). Franklin *et al.* acknowledge that the social model of disability distinguishes between impairment, the loss or limited functioning

experienced by an individual, and disability - the barriers that people with impairments face because of the way in which societies are structured, remarking that 'These barriers may be social, cultural, material, physical or attitudinal and they exclude people with impairments from mainstream life' (2018, pp.2-3). These barriers to participation have been discussed by critics including Stine Hellum Braathen, whose 2006 study of albinism in Malawi highlighted a lack of awareness among the people she interviewed about the causes and consequences of albinism. She remarks on the lack of availability of sunscreen and visual aids, and discusses exclusionary attitudes founded on the distinctive physical appearance of PWA, which lead to cultural stigmatization and prejudice (Hellum Braathen and Insgstad, 2006).

In comparison to other countries such as Tanzania, the situation of PWA in Malawi has received little critical attention, despite the recent escalation in attacks on people with albinism. The Republic of Malawi is a landlocked country in south-eastern Africa, bordered by Mozambique, Tanzania and Zambia. Lake Malawi, one of the largest and deepest lakes in the world, accounts for almost one-fifth of the country's area. According to the 2018 census, Malawi has an estimated population of 17.5 million (World Bank 2019) of which an estimated 10,000 people have albinism (Amnesty, 2019). Malawi's economy relies predominantly on agriculture, leaving the country vulnerable to external factors such as weather, population growth and environmental degradation, and it remains one of the poorest countries in the world. Human insecurity characterises the lives of many people in Malawi, but, as Ramesh Thakur reminds us, it is not war or genocide that poses the biggest threat, but 'soft threats', including poverty, a lack of safe drinking water and sanitation, hunger and disease (2013, p.123). A 2019 World Bank report remarks that 'Infrastructure development, the manufacturing base, and adoption of new technology are low, and corruption levels remain high with Transparency International ranking Malawi at 122/180 economies in 2018' (World Bank, 2019). Economic instability, a lack of access to essential health services, and inadequate housing make the lives of many Malawians difficult. Against this backdrop of

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insecurity, the multiple challenges of living with albinism in Africa position PWA as a particularly vulnerable group.

We draw on the findings of community based participatory research undertaken by Patricia Lund and Boniface Massah in central Malawi between 2015 and 2018 which investigated the challenges those with albinism faced at various stages of life, where concerns about security issues were one of the themes identified following a spate of attacks on PWA in the country. The study highlighted various support structures that identified key facilitators and agents supporting these vulnerable families. A qualitative descriptive design with purposive sampling and open-ended interviewing was employed, with all volunteers giving informed consent. During annual field work in August and September of each year, interviews in the vernacular Chichewa language were conducted with 10-15 families, transcribed and translated into English, and analysed thematically. These families were located near Blantyre (semi-urban) or on the banks of Lake Malawi (rural villages). At the time, some participants wanted their own names to be used, but these, and their exact locations, have been excluded from quotes here to maintain anonymity. In addition, albinism training days for education professionals and practicing teachers were conducted annually in English near Blantyre where 20-30 educators each year participated in focus group discussions where outcomes were discussed with the whole group, agreed and recorded anonymously. Again, fears about the security of pupils with albinism in schools was a major discussion point.

In this article we explore the roots of the attacks on PWA in the beliefs associated with albinism, examine the various threats to the personal security of PWA, and explore how these are being mitigated by various formal and informal responses and strategies put in place at different levels of society in Malawi. We highlight the different ways in which PWA protect themselves, which are revealed in our research findings, and consider how greater security can be provided in the context of increasing uncertainty by underscoring the importance of awareness and action at multiple levels, from the individual to the international. In pursuing

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these questions, we engage with critical work in the field of human security studies.

With the end of the Cold War, critics turned their attention from state power to power relations within the state. While conceptions of human security vary widely, the 1994 UNDP Human Development Report authored by Mahbub ul Haq set the tone for all succeeding definitions by articulating a universal, preventive, ‘people-centred’ approach that focused jointly on ‘freedom from fear and freedom from want’ (UNDP 1994). Human security studies have broadly focused on ‘the protection of individuals from risks to their physical or psychological safety, dignity and wellbeing’ (Tadjbakshsh and Chenoy, 2007, p.3). In this regard, human security and human rights are mutually reinforcing. Importantly, human security positions the individual as the reference point, rather than the state. As Sabina Alkire, the author of ‘A Conceptual Framework for Human Security’, explains:

Human security is people-centred, not threat-centred. Human security is a condition that results from an effective political, economic, social, cultural, and natural environment, and not from executing a set of administrative procedures. But to uphold human security effectively, a proactive attitude towards threats – whether they are sudden threats such as an earthquake or the ongoing threats faced by the destitute – is essential. (Alkire, 2003)

The 1994 UNDP report defines human security as i) safety from chronic threats such as hunger, disease and repression and, importantly for our discussion here, ii) protection from sudden and hurtful disruptions in the patterns of daily life – whether in jobs, in homes or in communities (UNDP, 1994). The report develops this definition in relation to seven dimensions of human security: personal, environmental, economic, political, community, health, and food security. The emergence of this people-centred notion of security responds to changing economic and political conditions often associated with globalization, which have generated disparities in wealth in many parts of the world, the eruption of violence and terror in the name of ethnic, nationalistic and religious identities and

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differences, and the trafficking of people, commodities and ideas and information across political and cultural borders (Mentan, 2014, p.vii).

Our interest here is in the personal security of PWA in Malawi and the many, sometimes intersecting threats—including those mentioned above—that position them as a particularly vulnerable group. Our focus on subjective understandings of security in this article reveals the perceptions of PWA of what makes them secure or insecure, and enables us to highlight local practices of human security. As Bruce Schneier observes in his study of security in an uncertain world, ‘Security is both a feeling and a reality. We’re secure when we feel protected from harm, free from dangers, and safe from attack. In this way, security is merely a state of mind. But there’s the reality of security as well, a reality that has nothing to do with how we feel. We’re secure when we actually are protected’ (2006, p.9). In focusing on subjective understandings of security, human security can be used as an analytical framework to produce context-specific knowledge about security. As Sara de Simone remarks, ‘The analysis of everyday informal practices of security is a vital element in building a bottom-up understanding of human security: these practices can help to shed light on the unequal distribution of security and on the power relations that stand behind it’ (De Simone, 2019). In focusing on these informal practices of security, our article points to the agency of PWA and those who endeavour to protect them, and aims to provide greater understanding of security priorities in Malawi.

### **Explanations for albinism in Malawi and their implications for security**

One of the greatest impediments to a person with albinism taking full part in society are the myths and beliefs that continue to be attached to albinism, which sit alongside different levels of understanding and acceptance of the biomedical explanations for albinism (Baker *et al.*, 2010). At albinism training days conducted by Patricia Lund near Blantyre in Southern Malawi in 2017 and 2018, teachers were asked to list the beliefs and stories about albinism in their community. Many of the beliefs that we recorded in Malawi are common across sub-Saharan Africa, as evidenced in an article by Andres E. Cruz-Inigo *et al.*, which lists common myths

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and misconceptions with regard to albinism in sub-Saharan Africa (2011), and our own work on the myths associated with albinism in southern Africa (Baker et al., 2010), and many of them are also attached to other disabilities. These beliefs have a profound effect on PWA from the moment of their birth until their death.

The teachers spoke about explanations for the birth of a child with albinism in the community, which is widely perceived to be the fault of the mother, that it comes from her side of the family or that she has been unfaithful or conceived while menstruating. Their responses reflect a wider tendency to blame women for congenital disabilities in traditional societies. For example, in Zimbabwe, Lund observed that when a young boy with albinism asked his father what had caused his albinism, the father replied that ‘his mother’s people’ were responsible (2001, p.5). Another explanation is that albinism can be caught, that it is contagious, or has been passed on as a curse. There are many references in secondary literature to the fact that if a person with albinism has touched food, it will not be eaten by anyone else (Masha, 2004; Baker and Djatou, 2007), which raises particular difficulties in a society in which food is often shared from a communal pot, and in which not offering food to a visitor is highly unusual. The notion that albinism is contagious leads to a number of different actions to avoid ‘catching’ the condition. Spitting is a common response to seeing a person with albinism, which is expressed by a female informant in Malawi who remarks, ‘Don’t look at a person with albinism when pregnant; if you do then spit and the curse is off’. We have recorded similar responses in South Africa and Zimbabwe (Baker et al., 2010), and Elvis Imafidon remarks on the same practice in Nigeria (2019). The belief that PWA are a curse was expressed by the teachers who commented, ‘if you laugh at someone with albinism, you will have a baby with albinism yourself’, a belief that is attached to other disabilities too. The teachers also mentioned that the ‘bush’ (traditional) doctors advise that sexual intercourse with a person with albinism is a cure for HIV AIDS; a belief that has been recorded in recent years across sub-Saharan Africa. These responses often lead to ostracism and marginalisation, which contributes to the vulnerability of PWA who can find themselves without social support networks.



The visible difference of PWA also inspires another set of beliefs which were articulated by the teachers engaged in the training days and focus group discussions that were part of these, who mentioned that PWA ‘have a layer of skin missing (the black layer)’. The repeated assertion of visible difference marks PWA apart in their communities; a notion reiterated by a male informant who commented that ‘They consider people with albinism are ‘skinned’ as they have lost the outer layer of their skin. That is like removing the skin of an animal, it is now possible to eat them.’ The informant considered this the reason why PWA were not considered human by some, and why they were mutilated and killed without conscience. A related set of beliefs expressed by the teachers is founded on a view that PWA are not fully part of the world of the living, that they are ghosts, that the mistake of an ancestor has been passed on, or that ‘if you laugh at a ‘nyau’ (a member of a secret society of the Chewa people in Malawi who often wear masks and perform dances) you will have a baby with albinism’. The notion that PWA do not fully belong to the world of the living is supported by the ‘death myth’ (Baker and Djatou, 2007, p.66), that they do not die a natural death but simply go into the bush and disappear, which is commonly heard in South Africa (Lund and Gaigher, 2002). Teachers participating in the training day expressed the belief that PWA do not die a natural death, they just disappear and, more specifically, that ‘they die or disappear before they reach the age of 40’. The lack of melanin in the skin of PWA is not only a visible difference, but makes them vulnerable to skin cancer, and without adequate health care, their life expectancy is limited. This may explain the assumption that ‘people with albinism disappear’. However, other teachers knew that albinism is an inherited condition and that it occurs ‘by chance’.

The value associated with the body parts of PWA was underlined in the focus groups. The teachers participating remarked that these body parts are used in charms to bring good fortune and wealth, as medicine, and as a solution for problems. They commented specifically that, ‘their bones are gold, they can be used for catching sharks as they are magnetic’ and another remarked that ‘their bones are diamonds that can be used to trap fish’. Schule points to an economic motive, remarking on that a commonality in accounts of the killings of persons with

albinism in Tanzania is that those buying body parts work primarily in two specific industries: mining and fishing (Schule, 2013), while Bryceson and Jønsson contend that the killings in Tanzania in particular 'are connected to gold and diamond miners' efforts to secure lucky charms for finding minerals and protection against danger while mining' (2010, p.354). The attribution of value to the body parts of PWA was reiterated by a member of the public participating in a focus group discussion who commented that 'People with albinism, they are witchcraft, they are diamond, they are wealth', an idea reiterated by another focus group informant who remarked that 'They are wealth for a businessman and bring success in an election. For example, if you take the leg of someone with albinism then a mine will produce gold (even if it is a tanzanite or uranium mine) and they will get rich'. This last set of statements reveals that the beliefs associated with albinism are manipulated for economic gain with the consequence that PWA are targeted for their body parts for use by witchdoctors. As Burke et al. observe, the oppression of persons with albinism 'cannot be understood only as arising from traditional beliefs, but also emerges for structural reasons which are related to rapid change and new forms of inequity in wealth and power' (2013, p.119).

### **'Behind two locked doors': The role of families and communities**

As a result of the economic value attached to their body parts, the threat of abduction is one of the most significant security risks faced by PWA in Malawi today, and heightened awareness of potential threats places restrictions on their daily movements in rural and urban settings. Children with albinism are among the most vulnerable members of society and their family members often play a front-line role in protecting them. They are young, not as physically strong as adults and, due to the visual impairment caused by albinism, may not observe that they are being watched or followed (CBM, 2016, p.4). In Malawi, many families decide not to send their children to school, sometimes because the education of other children is prioritised, but often because of concerns about their security as they travel to and from school, and while they are there (Lynch et al., 2011). This decision can have a significant impact on those children's learning and their life potential. In her

report on her mission to Malawi in December 2016, Ikponwosa Ero remarks that:

Persons with albinism, and parents of children with albinism, live in constant fear of attack. Many do not sleep peacefully and have deliberately restricted their movements to the necessary minimum, during daylight hours and when escorted by trustworthy persons. Mothers have sent their children to live with relatives or to boarding schools. Yet, even there, fear remains. Staff of boarding schools are concerned for the safety of their students and such establishments are in immediate need of security measures (A/HRC/34/59/Add.1, 2016).

As many children go to school at a regular time, in uniform and along a specific route, they are easy to identify, follow and target, particularly in isolated locations. On a rural field visit in central Malawi, the carers of a 13-year-old girl, the last born of four children and the only one with albinism, reported that she walked to school daily, always accompanied by peers, but that otherwise the family did not allow her to go far from home alone. This family had a relative with albinism and had accepted their daughter from birth. Their house was next to a thoroughfare en route to the local trading centre, and people were constantly passing by, so the family felt that during the day she was safe, because ‘everyone can see her’, but that this was not the case at night. The family borrowed a door from a neighbour who was in the process of building a house, but now the neighbour wanted their door back and their opening would have only a cloth covering, scant deterrent against intruders. The family reported that their local chief, the person responsible for their security, was supportive. A volunteer group from a UK university sponsored the village carpenter to build a sturdy door for this family, with a robust lock and hinges.

Individuals can take a range of initiatives to mitigate risks in going about their everyday life, by travelling with companions or by providing their families with details of where they are travelling and when they will return home. Mobile phone technology has the potential to make a real difference here, although it is still

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not easily accessible to the most rural communities in Malawi. However, for those unable to protect themselves or who are particularly threatened, such as children, young women and the elderly, families play a key role, ensuring protection within the home and the village, but also advocating for them and ensuring that they have a network of protection that extends into the wider community. Communities are crucial, not only to the acceptance and integration of PWA, but also to their protection by acting collectively to ensure their security and to defend them in case of attack.

In a rural village of central Malawi, the family of a six-year-old girl with albinism explained that they had had no concerns about her security until three attempted abduction attempts highlighted the very real threat she faced. The child's father had rejected her when she was born, but the maternal side knew others in the community with albinism and described her birth as a 'Gift from God'. In one event, a vehicle with two men inside stopped and they attempted to entice her to come to them, but members of the community had rescued her and returned her safely home. While the family had reported the events to the local police, even though the police station was some distance from their village, they were unable to act as the registration number of the car had not been recorded. The police told the family to protect the girl and to bring the licence number to them if they saw the vehicle again and they would try to trace it. While meeting with the family, one of the researchers was concerned that the young girl was listening to this conversation and looking sad, with her head in her grandmother's lap. When she mentioned this, the grandmother was insistent that 'She must listen. She must know that she cannot go to strangers'. However, it is not only strangers who are potential threats. In many cases, neighbours and close family members, even fathers, have been implicated. Since the abduction attempts, the family have always tried to send a trusted adult family member to collect the girl from school so that she returns safely, and they ensure that there is always someone present in the family home to protect her. This example underscores the role of individuals and communities in ensuring the security of PWA. They are not simply the beneficiaries of a model of human security that is delivered from the state or other institutions, but active

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subjects in the everyday security of members of their families and communities (De Simone, 2019).

The attacks and killings of PWA have particularly affected women and children who are exposed to multiple and intersecting forms of discrimination. Women and teenage girls are particularly vulnerable, not least because of the contemporary myth, mentioned previously, that sexual intercourse with women with albinism is a cure for HIV AIDS. As we remark elsewhere, ‘psychologically and physically, women with albinism are likely to be more vulnerable to predatory men, but the consequences are far-reaching, as AIDS is transmitted to husbands and children’ (Baker et al., 2010, p.176). A young professional woman with albinism told us that she always slept behind two locked doors to feel safe at night - the main one to the house and her bedroom door. She was able to afford this level of accommodation, which meant that she could protect herself, but many in Malawi cannot, which suggests that low-income earners are at greater threat of attack and abduction. Often, rural houses are made of sun-dried bricks with openings covered with wooden frames and mesh. The main opening to the house and any windows may be covered only with a hanging cloth, providing insufficient protection from intruders.

Providing an example of an effective strategy for resisting abduction, a mother related the story of an attack on her 14-year old daughter with albinism to us. They lived in a remote village in eastern Malawi where the inhabitants were mostly women and children. It was a moonlit night when the mother heard something in the yard at around 1am and called out. Four men entered the house and grabbed her daughter, while four other men stood guard outside to ensure no-one came out of the house next door, where a female relative was sleeping. The attackers were not from the village. Upon leaving the house, the men split into two groups to go in two different directions along small paths through the maize field. As the moon was bright, the female relative saw which group had the girl and followed them, carrying agricultural implements as weapons, shouting and screaming. The men had difficulty carrying the young teenager and eventually left

her and ran off. The father had another wife and usually lived with her, but the police called him and he was asked to sign an agreement that he would now stay with this wife to protect her and his daughter with albinism. The guidelines issued by the Christian Blind Mission (CBM) support the action taken by the women (2016). Usually, security professionals advise victims not to resist during a kidnap attempt to increase their chance of survival, but it is recommended that, because of the particular threat of attack for PWA which is highly likely to result in mutilation or death, they fight and shout for help to alert others to come to their aid. As the example of this 14-year-old girl shows, a struggling victim may convince attackers to abandon their attempt.

While PWA are often targeted in their own homes, they can also be vulnerable to attack when travelling between different locations. Jean Burke observes that ‘people with albinism often seek to protect themselves from being attacked by hiding or restricting their activities, travelling with a companion for protection, or seeking protection in other areas or countries that are considered safe’ (2019, pp.163-164). In a 2016 report, Amnesty International remarks on the same behaviour in Malawi:

Most people who attack [PWA] are close relatives. The attacks have also made well-wishers overprotective. One time I wanted to take a ride in a taxi to a hotel. People demanded to know if indeed the driver was going to drop me at the hotel. Even parents of children with albinism have become overprotective. I met one mother in Chitipa who was hiding her children out of fear. (2016, p.21)

In urban areas, PWA must be cautious when using public transport for fear of abductions, and those using bicycle taxis must ensure that they only use riders they know (Amnesty, 2016, p.35). They must often restrict their movement to daylight hours in both rural and urban areas. To mitigate these restrictions, individuals often have to rely on being accompanied by family members and friends, but these mitigation strategies mean having to pay additional fares for their journeys or increased travel time. For example, on journeys where one would normally take

one bus, a person with albinism may have to take two because they cannot use less secure shortcut routes (Amnesty, 2016, p.36). The impact of constant vigilance on PWA can be considerable. David, a 46-year-old teacher with albinism, told Amnesty International that each time he travels, his wife constantly checks on him. His children have been sensitized about the attacks to the point that if he is not home by a particular time they will be anxious about his safety. Each time the children hear news about an attack on a person with albinism they tell David. His personal security has become a preoccupation for the whole family (Amnesty, 2016, p.28). In his study of security in an uncertain world, Bruce Schneier remarks that, ‘We constantly make security trade-offs, whether we want to or not, and whether we are aware of them or not. [...] Security is pervasive. It is second nature, consciously and unconsciously part of the myriad decisions we make throughout the day’ (2006, p.9). For PWA, security must always be at the forefront of their minds, and this in turn has tangible consequences. As Franklin *et al.* remark, 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 (2018).

While families and communities have an important role to play in protecting PWA, and especially the most vulnerable, teachers also often find themselves on the front line and can play an important role in protecting children with albinism. As respected members of the community, they are well positioned to challenge misconceptions about albinism, to lead by example in taking positive action and to put strategies in place to enhance the security of children with albinism. Several of the teachers participating in a training session on albinism in central Malawi reported measures they had taken to ensure the safety of their pupils with albinism. Some had arranged a ‘buddy system’ for children with albinism so that they had a peer to help them in class and to ‘protect’ them during break time. Others had arranged for children with albinism to be accompanied to and from school and encouraged the local community to be vigilant and alert to any ‘strange behaviour’. The head teacher of a private school explained that she had organised a drama performance to educate parents on albinism. These examples demonstrate ways in which some

teachers go above and beyond to ensure the success and security of their pupils with albinism. Currently in Malawi, many children with albinism are not enrolled in school. The teachers involved in the focus group all felt that children with albinism should attend school regularly but commented that some children with albinism were being kept at home as they were ‘not considered important’. Those that do attend are either placed in specialist schools for the blind or attend mainstream schools with additional support from specialist resource centres.

### **‘We are human beings, just like you’: The power of self-advocacy**

In recent years, a number of role models for PWA have emerged in Malawi. These individuals demonstrate the potential of PWA to contribute to their societies, but are also important spokespersons for the albinism community. Among them is musician Lazarus Chigwandali, who is using his talent to raise awareness of albinism. Lazarus made a basic living by busking before he was noticed by Johan Hugo, a Swedish-born, London-based musician. Recollecting his early life-experience of violence and marginalization as a person living with albinism in Nankumba village, Lazarus says ‘People would come and beat me up for no reason ... Even when I was walking around the village, people would just throw stones at me. If I went to watch a soccer match, people would stop playing and leave the field because they didn’t want to associate with me’ (BBC, 2019). However, rather than being negatively impacted by this stigmatization, he remembers how his young brother, Peter, who also had albinism, positively influenced him to begin making and playing home-made banjos. The brothers began to compose songs about life in the village and, once their talent was recognised, they found themselves being embraced by the same people who had once shunned them and invited to play at weddings and christenings (BBC, 2019). When Peter developed skin cancer and subsequently died, Lazarus was forced to leave the village for the capital Lilongwe to busk on the streets. While he earned enough to support himself, this was at considerable personal risk, not just exposing him to the danger of being attacked, but also to the sun and increasing his risk of skin cancer.



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When Hugo, a Swedish-born, London-based music producer saw a video of Lazarus playing, he was impressed with his performance. Hugo is known for his production work with artists such as Mumford & Sons and Self Esteem, and also as part of the Very Best, his collaboration with the Malawian singer Esau Mwamwaya, who he worked with to initiate the collaboration with Lazarus. Mwamwaya had made contact with Lazarus, who agreed to join Hugo for a recording session at a lodge outside Lilongwe. However, a few days before they were due to begin, Lazarus disappeared and Mwamwaya could find no trace of him in Lilongwe. They eventually tracked him down in his home village, where he had fled with his wife and young sons. As Hugo later explained, ‘We realised we had been stupid. We hadn’t understood the terror that people with albinism live with every day, the suspicion of people’s intentions’ (The Guardian, 2019). They eventually collaborated to produce Lazarus’s first single, Ndife Alendo (We are Strangers), released in early 2019, in which Lazarus sings about how we are all visitors on Earth, who will one day return home to Heaven; a metaphor for the plight of PWA. Lazarus remarks in a BBC interview that, ‘We are treated as if we are visitors in their own land, so I’m telling people, ‘We are human beings, just like you’ (2019). His story conveys the threats and violence that PWA are subjected to, but also shows the resilience of some PWA in Malawi to overcome their marginalisation. The recognition that Lazarus has received has helped him to gain self-acceptance and allows him to use his music to change attitudes and call for greater inclusion.

### **Media and civil society responses**

The local and national media are well positioned to advocate for the rights of PWA and have played an important role in reporting the escalating violence against them in Malawi. In their study of the role of the media in advancing the rights of PWA, Massah *et al.* confirm that the media have been a key stakeholder in the fight against violence. Media coverage in Malawi has raised awareness about the escalation of incidences of violence, abductions and murders of PWA, and has facilitated public engagement on the issue, as well as construction of the issue

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as a priority national concern (Massah et al., 2017). However, while the media can play an important role in disseminating important messages about albinism to the general public, poorly informed news articles can pose a threat by communicating inaccurate messages about albinism, perpetuating misunderstandings, or highlighting information that can lead to an aggravation of the threat to PWA. Ikponwosa Ero remarks in her 2016 report that there has been a disproportionate reporting of cases of attacks and discrimination, rather than the presentation of more positive images of persons with albinism; a balance that repeatedly casts albinism in a negative light. Paradoxically, in attempting to report on the security threats to PWA, discourses of danger and safety are being perpetuated rather than overcome. Ikponwosa Ero suggests that it would be prudent to train media professionals on the scientific explanations of albinism, how to report freely without incentivizing criminals and the technique of repeated positive imagery to counteract frequent negative reporting (A/HRC/34/59/Add.1, 2016).

Civil society groups have done much to raise awareness and advocate for PWA, as the work of the Association for Persons with Albinism in Malawi (APAM) demonstrates. APAM provides a network for PWA in Malawi, advocates for them and engages with communities, other civil society organizations and the government on their behalf. APAM also provides daily essentials such as sunscreen and protective clothing to prevent skin cancer and eye damage. The organization provides scholarships and educational material to children with albinism so that they can stay in school and provides vocational training and resources for businesses led by PWA. They also play an important role in raising awareness and albinism advocacy in Malawi. In a recent effort to challenge the beliefs associated with albinism, APAM organized Mr and Ms Albinism, the country's first ever beauty pageant for PWA, which was held in Lilongwe in September 2019. One of the participants Patience Phiri told VOA News, 'I am here because I have ever experienced the threat. Even my real friends I chat with, they have even said I am money. This has really affected my family because they are there, just to protect me' (2019). Importantly, APAM also advocates for local law enforcement and government agencies to protect PWA. As we examine in the following section,

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government and the international community also bear a responsibility to act to protect PWA from harm.

### **National and international responses**

The role of the international community has been crucial to bringing international attention to the plight of PWA in Malawi, but also to leveraging action on the part of the government. In June 2015, the United Nations Human Rights Council appointed Ikponwosa Ero as the first Independent Expert on the enjoyment of human rights by persons with albinism. In her first two reports to the UN Human Rights Council, the Independent Expert, herself a person with albinism, expressed the need for coordinated national and international levels efforts to address discrimination against persons with albinism, and to ensure their access to health and social services. The mandate includes engagement with states, UN agencies, programmes and funds, and national human rights institutions to identify, exchange and promote good practices relating to the realization of the human rights of PWA and their participation as equal members of society. It also involves the gathering and exchange of information on violations of the rights of persons with albinism, the support of national efforts for the effective realization of their rights, and the raising of awareness on the rights of persons with albinism to combat stereotypes, prejudices and harmful practices. Importantly, the Resolution also recommends the integration of a gender perspective to pay specific attention to the multiple, intersecting and aggravated forms of discrimination faced by women and girls with albinism.

The UN Independent Expert Ikponwosa Ero has played an important role in bringing about action on the part of the government of Malawi. In March 2015, the government of Malawi developed a national response plan in conjunction with stakeholders. President Peter Mutharika issued a statement condemning the wave of attacks on PWA. He called on the police to arrest perpetrators and protect those with albinism and their families from risk of attack. However, while Ikponwosa Ero welcomed the launch of the National Action Plan during her country visit to Malawi in April 2016, she noted that the ‘absence of resources attached to the

plan has drastically delayed its implementation and such an emergency situation needs an emergency response' (OHCHR, 2016). She called for court sentences to reflect the gravity of crimes, recommended training for police, prosecutors and magistrates, and greater cooperation between the police and the courts. While the Independent Expert commended the protection measures adopted by communities, she underscored the need to address the root causes of attacks, commenting that 'It is worrying to note that witchcraft beliefs and practices are widespread in Malawi, although often a taboo topic' (OHCHR, 2016).

In June 2018 a new national action plan was launched to protect and promote the rights of PWA. The National Action Plan on Persons with Albinism in Malawi 2018 to 2022 aims to guide efforts to address challenges persons with albinism face in areas including education, health, empowerment, protection and human rights. Importantly, it calls for continued collaboration among stakeholders to ensure successful implementation of the plan. In 2019, the widely reported killing of Yasin Phiri on New Year's Day prompted calls by local and international civil society and by the UN Independent Expert for government action. While there have now been some arrests for crimes related to albinism, concerns remain about the legitimacy of police investigations and the appropriateness of sentences. In March 2019, the government announced cash rewards of five million kwacha to anyone providing credible information in relation to conspiracy to abduct or kill persons with albinism. In another example of positive action, Kasungu Police Station distributed personal security alarms to PWA in the local area (AllAfrica.com 2019). However, to achieve real change and genuinely ameliorate the situation of PWA in Malawi, a more coordinated and government supported plan of action is needed.

## **Conclusion**

A focus on human security in recent years has highlighted new priorities for global security agendas, including attention to the vulnerability of individuals to oppression and physical violence, interconnected threats such as vulnerability to poverty or conflict, and the responsibility of the state to protect people in these

situations. Importantly, human security focuses attention on the role of actors other than the state as sources of threat, but also on the role of these actors as holders of obligations to protect vulnerable individuals and groups. However, it is essential to focus too on the security practices that people employ in order to feel secure. As De Simone observes, “These practices, even more than people’s own conceptualisation of security threats, can help to shed light on structural dynamics of power relations that produce insecurity beyond the locality’ (2019). The informal practices of individuals and groups communicate local understandings of security and how it can be achieved, but also expose differences in vulnerability and insecurity that influence people’s behaviour. These behaviours are rooted in beliefs that influence people to marginalise or exclude PWA, but which can also motivate them to offer them protection.

The security of people living with albinism in Malawi today relies on individuals adopting safety measures in their daily lives, and families and communities being alert to the various threats and aware that they need to take effective action to protect PWA. The findings of our fieldwork highlight numerous examples of effective strategies to ensure that PWA can go about their daily lives in greater security, although they also underscore the significant challenges posed by poverty and inadequate infrastructure. Greater security can be provided for PWA in Malawi in the context of increasing uncertainty through awareness raising and action at multiple levels, from the individual to the international. Individuals, albinism associations, civil society and the media all have an important role to play in enhancing understandings of albinism, challenging the negative beliefs associated with albinism, and changing societal attitudes. The example of self-advocacy by Lazarus, who is reaching communities across Malawi with positive messages about albinism through his music, shows that some of the solutions to the plight of PWA can be generated locally.

At the same time, it is clear that national organizations such as APAM have an important role to play. On International Albinism Day 2019, the National Coordinator of APAM, Overstone Kondowe, called for action: ‘We are human

beings too and have an equal right to be included in society and live in safety. The National Action Plan on Persons with Albinism in Malawi is designed to deliver this in all areas of life including education, employment and safety, but policies mean little if they are not delivered. We need to see concrete actions and plans being implemented' (Sightsavers, 2019). To effect long-term change, the government of Malawi and the international community must adopt a coordinated collaborative stance to effect which extends through education, healthcare, monitoring and reporting, policing and the criminal justice system.

## Note

1. Ethical approval was given by the Research Ethics Committee, Coventry University, Project P35733 and the project involved close collaboration with the Association of Persons with Albinism in Malawi (APAM).

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