



## Research article

## Living with albinism in an African community: exploring the challenges of persons with albinism in Lilongwe District, Malawi

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## ABSTRACT

**Background:** Albinism is a genetic condition caused by a deficit in the production of the pigment called melanin, which protects the skin against ultraviolet light and provides the skin with its color production. The condition may predispose persons with albinism (PWAs) to lifelong physical and health problems, such as visual impairment and ultra-violet induced skin damage. Due to this condition, we explored the challenges faced by persons living with albinism as they socialize in Lilongwe District, Malawi.

**Method:** The study adopted an interpretative phenomenological approach and included 30 participants comprising 13 females and 14 males with albinism and three key informants from Association of People with Albinism in the Lilongwe district in Malawi. Data were collected through in-depth interviews and focus group discussions. Van Manen's (2014) six steps of phenomenological analysis was used to analyze all data.

**Results:** People with albinism face a variety of problems, the most common of which are financial constraints, health complications due to a lack of adequate medical care, a lack of community support leading to stigma and discrimination, and superstitious beliefs.

**Conclusions:** People with albinism suffer socially as a result of misconceptions, behaviours, social isolation, labelling, and beliefs that are negatively correlated with their disorder. PWAs face these problems as a result of public misunderstanding about albinism.

## 1. Introduction

Oculocutaneous albinism is a group of four autosomal recessive disorders characterized by hypopigmentation of the hair, skin, and eyes due to a total lack or reduction of melanin biosynthesis in the melanocytes (Gronskov et al., 2007). Albinism, as it is widely known, is a genetic condition caused by a lack of melanin formation (Franklin et al., 2018). Melanin is a pigment that protects the skin from ultraviolet light and helps it produce color (Franklin et al., 2018). People with albinism have different levels of melanin, which causes variations in skin tone, hair color, and eye movements. The disease begins at birth and lasts for the rest of a person's life. Albinism can predispose people to lifelong physical and health problems, such as vision impairment and ultra violet skin damage, which can lead to skin cancer. This genetic disorder can be passed down from either parent and is difficult to prevent, particularly if both parents are unaware of their family history. If both parents have albinism or bear the gene, their children are more likely to be born with it. Poverty, exposure to harsh sunlight, and a lack of access to adequate health care, especially in rural areas, can exacerbate these health issues (Lynch et al., 2014).

The total prevalence rate of albinism in Africa has been estimated to be 1 in 5000 people (Wright et al., 2015). In Malawi, albinism affects an estimated 134,636 people, with 17,156 people living in urban areas and 117,480 in rural areas (Malawi Population and Housing Census Report, 2018). It is unclear why the prevalence of albinism has risen so dramatically in Malawi, especially in rural areas. It is thought to be linked to cultural customs, in which certain traditions marry from the same blood lineage (Lund et al., 2007). Furthermore, as the country's population grows, the prevalence rate of albinism may rise in different parts of the country. Throughout history, people with albinism in some African countries, especially Malawi, have been exposed to inhumane attacks for a number of reasons. In a joint report published in February 2018, the Malawi Police Force and the Ministry of Justice and Constitutional Affairs reported at least 148 cases in four Malawian provinces (Amnesty International, 2018).

In Africa, there is an increasing awareness and acceptance that persons with albinism should be considered disabled (Franklin et al., 2018). People with albinism are considered disabled in Malawi

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because their conditions prevent them from participating in everyday activities. Although the [World Health Organization \(2011\)](#) defines disability as an umbrella concept that encompasses impairments, activity limitations, and participation limits, whether albinism can be classified as a disability is debatable. Individuals, particularly those with ocular albinism who work without any physical or medical assistance, do not recognize or adopt a disability mark ([Franklin et al., 2018](#)).

People with albinism in African cultures view their environments as hostile because institutional and national interventions do not benefit them. It is thought that social institutions are not set up well enough to handle PWAs. Poverty, inadequate access to medical care, a lack of conducive learning environments and services, a lack of community empowerment, limited engagement in community events, prejudice, and stigma all have an effect on people with albinism's well-being in Africa ([Nyamu, 2014](#)). The lack of reliable numbers, systematic follow-ups, and information on the location of people with albinism makes it difficult for stakeholders and service providers to completely meet their basic needs, particularly in rural areas in African communities. Others, such as students, family members, and community members, have a hard time understanding albinism, making it difficult to provide assistance.

In some societies in Africa, educational centers, for example, are not sufficiently prepared to provide advanced education for people with albinism ([Ndirangu, 2014](#)). Furthermore, teachers, school administrators, and educational supervisors also have a limited understanding of the learning needs of students with albinism ([Ndomondo, 2015](#)). Mostly students with albinism in some African communities, who are usually visually impaired, may be left without assistance such as additional instruction, optical aids, special text books, modified tests, and other learning materials with enlarged prints that are needed to learn successfully. Discrimination against people with albinism in schools has the potential to lead to a high rate of illiteracy among them. Because of the fear of kidnapping and killing, children with albinism are often required to be accompanied to school by relatives or teachers ([Impress Media Australia, 2020](#)).

Furthermore, attacks, threats, killings, abductions, possession of body parts, and exhumation of the graves of people with albinism in some communities in Africa have traumatized family members who have seen their relatives' dismembered bodies ([United Nations, 2016](#)). The President of Malawi and the Minister of Gender, Children, Disability and Social Welfare publicly condemned the attacks on PWAs in March 2015 ([Amnesty International, 2018](#)). In 2016, the United Nations country team in Malawi developed a program in partnership with the government and civil society to improve the security of people with albinism and prevent further abuses. This included a wide range of initiatives such as advocacy and education about the rights of people with albinism, funding for improved community-based security systems, ongoing investigations and prosecutions, a review of investigated and prosecuted crimes, an audit of all cases reported to the police, and a study of the root causes of the abuse on PWAs ([Action on Albinism, 2020](#)). Other initiatives include prosecutor and investigator training, the development of a prosecutor's handbook, education and health interventions, capacity building of the Association of Persons with Albinism (APAM), including human rights monitoring and reporting training, support for creating a national action plan on albinism in place of the national response plan, advocacy, and communications ([Action on Albinism, 2020](#)). Despite these public interventions, the plight of persons with albinism in Malawi is still a major concern. Scholars such as [Braathen and Ingstad \(2006\)](#), [Lynch et al. \(2014\)](#), and [Schwering et al. \(2015\)](#) have conducted albinism research in Malawi (2015). Despite the fact that such studies have been conducted, little is known about the challenges faced by PWAs in Malawi. As a result, this study aimed to fill a research void by examining the problems faced by people with albinism in Malawi's Lilongwe District.

## 2. Method

### 2.1. Study design

The research was carried out in Lilongwe District, Malawi's capital city in Southern Africa. Lilongwe District is home to the Association for People with Albinism in Malawi (APAM). This influenced our decision to conduct the study in the Lilongwe District. The study was conducted using a qualitative research approach. An interpretative phenomenological methodology was chosen because it offers insight into the living experiences of people with albinism ([McMillan and Schumacher, 2010](#)). Purposive sampling approach was used to recruit a total of 30 participants. Purposive sampling is the deliberate selection of a participant based on their characteristics. This entails locating and choosing individuals or groups of people who are particularly informed or experienced about a phenomenon of interest ([Cresswell and Plano Clark, 2011](#)).

The participants included 13 females and 14 males with albinism. In addition, three key informants from APAM were chosen. Since APAM is the official association in Malawi that works with the government and other agencies to improve the living standards of PWAs, they were included as a key informant. They provided us with useful information about the conditions of PWAs and connected us with them so that we could collect data. With the help of an interview guide, data was gathered through in-depth face-to-face interviews and focus group discussions (FGDs). Participants' verbal consent was obtained prior to their inclusion in the study, and they were informed of their right to withdraw at any time. We obtained participants' permission to use a voice recorder prior to the interviews and focus groups. Participants were given the assurance that the details they provided would be kept confidential and anonymous during the analysis. All participants' real names were replaced with pseudonyms to ensure anonymity and confidentiality. Since the participants were fluent in Chichewa and able to express their experiences well, the interviews and focus groups were conducted in that language. Before the focus groups, each participant was interviewed individually. Each interview was 50–60 min long.

Focus group discussions were chosen because they encouraged participants to feel a sense of mutual identity and unity, as well as help group members learn from one another and share and build on each other's perspectives ([Kitzinger, 1994](#)). When interviewing participants who are disadvantaged, stigmatized, or feel insecure, focus group discussions are generally beneficial ([Kitzinger, 1994](#)). Two separate focus group discussions (FGDs) among PWAs were conducted by the researchers. PWAs were divided into two gender-balanced classes. The focus group discussions lasted two to two and a half hours. The focus groups were used to see if any of the issues faced by PWAs were shared by both males and females. The purpose of the key informant interviews was to triangulate data and confirm the PWA findings.

### 2.2. Data analysis

The data was played and listened to several times before transcription, and the researchers then translated the data into English. Interpretative phenomenological analysis was used to examine the translated results. [Van Manen \(2011\)](#) six stages of phenomenological analysis were used by the researchers. We read the explanations of the participants over and over before we grasped what they had written. The importance of meaningful sentences, statements, or words in relation to the phenomenon under inquiry was highlighted. Different statements, whether they were common or similar, were grouped together into theme clusters. The themes' connections were described and summarized. Sub-themes were formed from regularities and sets of similar concepts, which were then compared ([Van Manen, 2011](#)). We checked whether the answers corresponded to their thoughts during the interviews to ensure that the research was trustworthy and reliable. To further minimize bias, participants were constantly asked to check the authenticity of anything that had been said or noted.

### Ethics approval

The study was subjected to ethical approval from the Ethics Committee for the Humanities (ECH) at the University of Ghana, the National Commission for Science and Technology, and the Ethics Committee for the Social Science and Humanities in Malawi, to ensure that the researchers worked within the expected research ethics limits. On March 9th, 2018, ethical approval was authorized to conduct the research.

## 3. Results and discussion

### 3.1. Socio-demographic characteristics of participants

The study selected 30 participants in total (15 males and 15 females) comprised of 27 PWAs and three key informants. The women were between the ages of 20 and 62 years whilst men were aged between 18 and 40 years. Regarding ethnicity, the study findings noted that twenty-one out of the twenty-seven participants were of the Chewa tribe normally found in the Central region of Malawi. Three participants were Tumbukas and one Ngoni, both from the Northern region. Two participants were of the Chawa tribe, mostly found in the Southern region of Malawi. However, all the participants lived in Lilongwe District. In terms of their educational background, 16 PWAs had no formal education, either lower primary or upper primary, and 11 had between basic and senior secondary level of education. All three key informants had university degree qualifications. Out of the twenty-seven participants, eight had various occupations that were their source of income. These included four who were doing casual work in the community, like cultivating other people's farms. Two of the participants were working as office messengers, while one was an administrator and one was a nurse. Four of the participants were students, while fifteen of the participants had no occupation, hence no source of income.

### 3.2. Challenges faced by persons with albinism

Barriers to education, attitude, a lack of awareness about albinism, economic constraints, stigma and discrimination, health care, and emotional problems arose as challenges faced by people with albinism. These challenges are presented in themes and discussed accordingly.

### 3.3. Barriers to education

People with albinism spoke about the difficulties they faced in school when they were younger. The problems in education usually began on the first day of school and lasted until the student graduated. To begin with, PWAs found it difficult to socialize with their peers while they were younger because of variations in their skin color and nystagmus. PWAs again claimed that they were unable to see from the blackboard during teaching hours due to vision issues, despite the fact that all of their peers were able to see without difficulty. Furthermore, participants reported that the font size in the textbooks used in class was too small for them to read comfortably. Reading problems were also a consequence of their nystagmus, which caused the letters in the books to become unstable, according to them. They confirmed the following in their responses:

*Due to the difficulties I faced in school, I did not perform well. When none of my classmates in class had a problem seeing what was written on the blackboard, I had a problem. That is why I was unable to finish my studies (Daniel - FDG1, male, LL rural).*

*I have a serious eye condition that has plagued me for a long time. I was unable to advance in school due to an eye condition. The letters in the books were shaky, making it difficult to read them clearly. (FGD2, female, Rachel, rural)*

In developing countries, educational institutions are ill-equipped to provide specialist education for people with albinism (Ndirangu, 2014).

Teachers, school administrators, and educational supervisors still have a limited understanding of the learning needs of students with albinism, especially in Africa (Ndomondo, 2015). Most PWAs do not receive help from their teachers in class because the teachers may lack the necessary training to deal with their needs. Owing to a lack of professional support, they struggle with their academic journey. The results showed that participants' experiences in both rural and urban areas in educational constraints were similar. Furthermore, no special educational facilities and resources for PWAs were discovered in both rural and urban areas. This research corroborates the widely held belief that people with albinism who live in rural areas or in low-income countries face greater social exclusion than those who live in developed countries (United Nations, 2016).

Another participant said that he had stopped attending school due to his fear of being abducted.

*People with albinism were being kidnapped and killed on their way to or from school, according to the reports. My family and I were scared, and I stopped going to school because of the ongoing killings (James - FGD3, Male, KAPRA- LL urban).*

Unfortunately, these difficulties, along with the problem of PWAs being abducted from schools for ritual purposes, cause them to drop out. Bullying, name-calling, ridicule, and derision are committed by both teachers and students, leaving PWAs feeling lonely and alienated (Wan, 2003). Students and teachers' psychological and physical exploitation of PWAs worsens their school experiences, leading to their dropout (Hong et al., 2006). According to Standing Voice (2021), an international non-governmental organization based in Tanzania, nearly half of children with albinism complete primary school, with just 10% progressing to secondary school. This is because many who do attend school still struggle to read and need vision aids in order to participate in class. The results on educational issues confirm PWAs' educational conditions in Tanzania.

### 3.4. Lack of knowledge about albinism

Participants expressed that lack of knowledge about albinism by their family members affected the way their parents took care of them, which resulted in complications with their skin. Because families were not knowledgeable on the care for albinism, they struggled to determine the best way of taking care of their children with albinism. For PWAs and their families, recent information about albinism and special treatment were received through the drama and sensitization programs organized by APAM and another NGO called Tiritonse. The participants recounted:

*My family didn't understand my illness because I was the only one in my village and the surrounding villages who suffered from it. My family was in a dilemma, unable to provide for my needs as an albino (Saul - FGD3, male).*

*I learned about the use of lotion on my skin from Tiritonse only six months ago. I had no idea that my skin color was a disease that required extra attention. I was going about my business as usual (Daniel - FDG1, male).*

Another participant noted that due to the lack of knowledge, sunscreen lotion was not effectively used on her skin:

*My parents were unfamiliar with my condition and the fact that it necessitated the use of a special sunscreen lotion. My skin used to get blisters that came and went, but I had no idea they were caused by the sun (Cynthia - individual interview, female - APAM).*

A key informant added that:

*Persons with albinism have limited knowledge on how to effectively apply sunscreen lotion to maximize their protection. Sunscreen is applied using small dots in the places exposed to the sun only. As a result of the ineffective use of the lotion, most PWAs have the misconception that sunscreen lotion with a higher protection factor is the best for them. (Key informant 1 - APAM)*

Generally, there is lack of knowledge regarding the special care that people with albinism need in order to function well in their daily life. This usually results in a lack of protective clothing, sunscreen and visual aids which are collectively vital to their daily functioning (Cruz-Inigo et al., 2011). As a result, persons with albinism tend to fail to accept their condition as they have little knowledge of the biomedical explanation of it (Braathen and Ingstad, 2006). The lack of knowledge means that there will be lack of vital items such as protective clothing, sunscreen and visual aids needed to function. The results of the research agrees with a study conducted in Uganda by Bradbury-Jones et al. (2018), which found that people with albinism and their community members have a limited understanding of their condition and commonly equate albinism with witchcraft, ghosts, sleeping with white men/women, and ancestral retribution.

### 3.5. Superstitious beliefs

The results showed that PWAs and their families had superstitious views about albinism due to a lack of knowledge about the disease. Persons with albinism thought their symptoms were caused by their mothers' anemia during pregnancy. Furthermore, it was discovered that some PWAs claimed their illnesses were caused by their mothers' blood transfusions during childbirth. The majority of albino women were born after their parents had given birth to other children who did not have albinism. They were persuaded that their older siblings cleansed their mother's womb, causing the PWAs to be born with thinner, paler skin. During focus group discussions, some participants believed that their mothers were cursed as a result of jealousy and envy in their families. This belief was revealed by their answers when asked what albinism is. As one participant put it:

*I think albinism is witchcraft related. I suspect somebody did something to my mother when she was pregnant. That is why I was born like this' (Sara - FGD3, female).*

Others shared different opinions regarding the beliefs on albinism:

*When my mother was pregnant with me, she was told she didn't have enough blood. Even when I was born, my mother was anemic, but by God's grace, I survived. So I'm not sure if my albinism is linked to a maternal blood shortage (Gladness - Individual Interview, female).*

*My family's firstborn had a very dark complexion, but the complexions of the other siblings gradually lightened. My parents were older when I was born, and I have a lighter skin than the rest of the family. That is why I am convinced that albinism is caused by being born when one parents is older. (Ruth - female FGD2)*

Traditional beliefs about albinism compel most parents to keep their child's secret at home, fearing ridicule from their community. People with albinism suffer from a number of misconceptions and perceptions that have a negative effect on their health. As a result, their lives come to an abrupt end. According to Hong et al. (2006), parents of albino children, especially mothers, are subjected to several myths about albinism's origin. Because of a lack of knowledge and reliable facts about albinism, the mothers are mocked by society, and their psychosocial well-being suffers as a result. Because of this, the quality of life for children with albinism may be compromised (Hong et al., 2006) as they are associated with the alleged immorality of their mothers and evil deeds. This superstitious belief supports previous research findings that PWAs are perceived to be immortal and therefore useful in rituals (Burke et al., 2014; Saffitz, 2018).

### 3.6. Economic restraints

People with albinism who lived in rural areas and relied on farming were particularly hard hit financially because they lacked support. The participants indicated that they are poor because their health prevents

them from working effectively, particularly in the sun. As a result, practices such as farming, which exposes them to the light, are always done on a small scale, resulting in a lack of resources such as money and food, preventing them from meeting their basic needs. To avoid the heat, the participants said they have to work early in the morning before the sun rises, which means they are less active. In addition, people do not offer persons with albinism jobs as they think that they cannot work. The participants said:

*When there is too much heat, my work is reduced. For example, I am unable to participate in a community project called "food for work," in which we assist in road clearing or perform community service in return for food or money. As a result, my financial situation remains stagnant, and I continue to live in poverty because the government is unable to keep me on the project because I am unable to function successfully in the sun like others. (Thomas, guy, FGD3)*

Another participant shared that they are disadvantaged in competing to secure jobs with pigmented skin people:

*... The majority of our pigmented friends have gotten very good jobs in town because they were able to do well in class, while I struggled and never achieved in school. It makes a huge difference in our lives... (William - FGD1, LL rural, male.)*

Persons with albinism are limited in their ability to participate in economic activity as a result of their disease. Unlike pigmented people, people with albinism have a limited job market. The demographic profile of PWAs revealed that few lived in urban areas and, as a result of their educational backgrounds, were employed in formal jobs. Many who live in agricultural communities inevitably become poor and beg as a means of survival because their skin is fragile and easily blisters under the sun due to their physical appearance and visual disability (Bryceson et al., 2010; Walton, 2012). In addition, due to their historical exclusion, people with albinism are disproportionately more affected by poverty than other groups of socially disadvantaged people (Bines and Lei, 2011). This has been evident since the beginning of the educational system due to a lack of appropriate educational provisions for them. The majority of them have been forced to drop out of school due to social discrimination. Later in life, people with albinism can have more trouble finding work that needs a strong educational background. This is due to the fact that they are less educated than the majority of the population (Hong et al., 2006). In developed countries like Australia, economic conditions for people with albinism are unique because people with albinism work in every area of Australian life, from running businesses and serving in government to raising children and representing citizens in parliament (Impress Media Australia, 2020).

### 3.7. Stigma and discrimination

In many societies in Malawi, when a child is born, his or her name is given depending on the family's situation at that particular moment. Persons with albinism are not exempt from this practice. Right from birth when a child with albinism is delivered, most parents have unanswered questions and this is expressed in the names given to the child. Some of the names express the meaning of how the child was welcomed into the family. In such cases, some of the meanings express bitterness such as "Mwatitha" which means "you have finished us" whilst others like "Mabvuto" which means "Trouble." express the problems ahead for both the family and society. This is due to the fact that the family is unaware of the implications of having an albino child. When mothers encounter marital problems as a result of giving birth to a child with albinism, certain names are often given to their children. Because of the children's albinism, some men suspect their wives of having sexual relations with white men, particularly in rural areas where there are white missionaries. Despite the fact that some families name their children with albinism with troublesome names like Chikondi (Love), Chimwemwe (Happiness),

and Mwai (Love), some families name their children with albinism with caring names like Chikondi (Love), Chimwemwe (Happiness), and Mwai (Happiness) (Lucky).

People with albinism were given additional names by their family members when they grew up, such as "Mzungu," which means "white guy." Their birth names were sometimes replaced by these pseudonyms. While the word "mzungu" has a positive connotation when used positively, it has also been used in a negative manner. When these names were given to PWAs, they elicited negative feelings like disappointment, annoyance, and rage. Their friends and community members called them names that were derogatory. The majority of the names were based on their skin color, which was characterized as "red." When people with albinism are in the presence of people who do not have albinism, this is a complete mockery, and it makes them feel discriminated against and stigmatized. PWAs grow up feeling inferior and less than in society because they are raised in such hostile environments. Any additional names that others can call them cause them to become defensive and upset. When more demeaning names were given by others, a participant experienced negative emotions and indignation, as shown below:

*I was disappointed and angry as a child because of the names that were assigned to me in my entire life... Both adults and children called me derogatory names at home. (Faith - female person interview)*

Furthermore, as society began to recognize albinism and the stigma PWAs faced as a result of derogatory names, it became more difficult to refer to people with albinism in Chichewa. The majority of people were unsure if using the word "alubino" was appropriate. As a consequence, some people prefer to use a descriptive sentence rather than a single word to be protected. Persons with albinism faced the same difficulty in communicating their desired identity or name for themselves as for people without albinism. Furthermore, seeking the most suitable words to apply to people with albinism was a challenge in this research. The key informant said the following when referring to people with albinism:

... 'Anthu angati amenewa' is used which means 'people like these ones.' (Key Information 2 – KAPRA).

The participants who were PWA themselves would say:

*anthu obadwa chonchife*, which means 'people who are born like this (us)'... (Sandra - FGD3, KAPRA, LL Urban).

Any minor misunderstanding of the language used to refer to people with albinism can easily disturb their emotions. This was found during the researcher's interviews with the participants. The researcher accidentally interchanged the terms "people with albinism" and "people living with albinism" at the start of the interviews. The participants described the difficulty and humiliation they faced while searching for accommodation in densely populated neighborhoods. Some landlords have stated that they would not allow albinos to live on their properties. A participant's response illustrated this:

*I was new to the community. My husband went to look for accommodation alone and he was offered a house. When we moved into the new house as a family, we were given back our money the following day and told to vacate immediately without any explanation (Gladness - Individual Interview, female - APAM).*

The participants also expressed that they encounter discrimination when they seek assistance from pigmented people in their community. They disclosed that:

*I was thirsty and went to a house along the road to beg for drinking water. The woman gave me water in a glass and I was so grateful. After drinking the water and handing the glass back to her, she immediately threw it on the ground and broke it in my presence with anger while chanting evil incantations. I was shocked at what I saw and I questioned myself as to what kind of discrimination it was (Hope - individual interview, male – MCM).*

*I was chased away like a dog or a thief when I knocked on the gate in a residential area when I was looking for casual work. I didn't understand what crime I had committed, asking for a job. Our pigmented friends really discriminate against and isolate us (Sara - FGD3, KAPRA, LL Urban).*

Furthermore, the participants expressed that they felt discriminated against and sidelined when they went shopping in the city. Most pigmented persons do not want to associate with or even speak to them. At times when they enter shopping centers to ask for the price of an item or to make a purchase, some shop owners give them a signal not to enter the shop. In some cases, when they enter the shop, most customers immediately exit. They were also openly discriminated against by their fellow community members during social gatherings such as weddings and funerals among others. These experiences made them feel pain and embarrassment:

*When I enter into a shop where there are pigmented customers who are buying or asking for a price, some of them immediately stop the transaction and leave the moment that they see me entering the shop (Brenda - FGD).*

The killings in Malawi have also contributed to the level of discrimination against people with albinism more than before.

*I have lived in the city of Lilongwe for my entire life, interacting freely with my neighbors and friends. However, the sudden killing of persons with albinism in Malawi in 2015 has affected my cordial relationship with my friends and the people who surround me. Most of my friends shy away from me and I am now the center of attention in one way or another in my community because most of my community members and friends see me from a different angle. Some of my friends, who were bold enough, told me that they are afraid that the police may take/arrest them as suspects. This is because immediate friends are usually targeted and picked for investigations (Sandra - FGD3, female).*

The participants further expressed their dissatisfaction with the way they are treated by stakeholders when it comes to projects concerning PWAs. Some of them stated that they are discriminated against and are not given the opportunity to participate in programs that benefit them:

*The government marked World Albinism Day by handing out millions of Kwachas in allowances to delegates who aren't even albinos... However, it does not even consider us for startup capital or economic empowerment, which would allow us to compete on an equal footing with people who are not albino. It would be beneficial if they could include us in the process of determining our requirements. Instead of albinism day T-shirts, we need to hear success stories (Sandra - FGD3, female, KAPRA, LL Urban).*

Some of the participants expressed being isolated by their own families because of their albinism. They also lamented that even in religious circles where one would expect to get solace and hope, people with albinism and their mothers experience stigma from their fellow church members:

*I cook my own meals separately from the rest of my family using different utensils. No one touches anything that I use. All of my family members do not love me and they do not want to be associated with me because I am the only one who looks different in my family and clan (Brenda - FGD2, female, LL rural).*

*When I started attending Sunday school classes, some of the church members told their children not to sit close to me or to eat with me because I was an evil child. The children would inform me of what their parents told them about me (Hope - individual interview, male – MCM).*

A key informant confirmed that:

*Yes, it is true that in some families and church members do not want to interact with people with albinism. Some elders are too quick to judge people with albinism and their mothers. They are looked down on at all the times as sinners (Key Informant 2 - KAPRA)*

Participants in this study agreed that physical appearance can often reflect how social interaction happens in societies. PWAs are also stigmatized as a result of their appearance. They are deprived of essential needs such as a sense of belonging, socialisation, and intimacy as a result of the stigmatization (Estrada-Hernandez, 2018). This stigmatization takes other forms, such as derogatory names, according to Bolt (2005) and Brocco (2015). People with albinism are given different names to denote their physical appearance, according to the findings, and these names are known among the population in communities where PWAs live. PWAs are often discriminated against and killed in their communities because they are believed to be cursed, and their existence triggers natural disasters such as droughts, floods, illnesses, and deaths. Machoko (2013, Machoko, Machoko, Machoko, Machoko, Machoko, Mach. Persons with albinism face discrimination based on a variety of factors, including their skin color, disability, gender, ethnicity, and age. This is particularly true in cultures where the majority of the population has dark skin; however, color discrimination has also been identified in predominantly white communities, where people with albinism are discriminated against because they are 'too white' (United Nations, 2016).

### 3.8. Health care challenges

The people with albinism also indicated that they experienced various health challenges. These challenges included visual challenges, hearing challenges, bleeding of the lips, skin conditions, the non-availability of sunscreen lotion, negative attitudes from health personnel and the accessibility to health facilities. Regarding the visual challenges, the participants mentioned that with bright sunlight, they were unable to clearly see objects and human beings unless they were in close proximity. They further noted that because of the visual acuity, they could see only shadows if they were not wearing glasses. He explained:

*I face a lot of challenges related to seeing things or even people, especially if I am not near them... My eyes hurt (Joy - Individual Interview, male - MCM).*

The hearing challenge was another issue that the participants mentioned. Some of the participants noted that they were able to hear very well if the one talking to them spoke with a high tone. During the interviews, it was observed that the participants turned their ears towards the voice of the interviewer to clearly hear what was being asked rather than facing the interviewer directly. The participants said:

*Since childhood, I have been experiencing problems hearing what people say if they are not loud enough. When I attend any social gathering and I sit at the back, I will miss most of the communication, unless I ask the person who is seated closest to me (Mary - FGD2, female, LL rural).*

The findings indicate that people with albinism experienced cracked lips. Out of the twenty-seven participants, four complained of having cracked lips that were painful and gave them a hard time. They lamented:

*Our lives are so miserable and painful due to the blisters on our skin and cracked lips without any cure (Joseph - FGD1, male, LL rural).*

Despite the aforementioned skin challenges, the participants indicated that the sunscreen lotion that is meant to protect them from the direct heat of the sun is sometimes not available in most of the hospitals. This means that the people with albinism do not have easy access to it. This forces them to buy it expensively from pharmacies. Sometimes, others resort to buying a cheaper lotion that is not recommended for them. Moreover, the participants complained that the knowledge of applying the sunscreen lotion only came after their skin was already damaged, thus the sun screen lotion was not very effective. They noted:

*Despite the fact that we are now using the sunscreen lotion, for some of us, our skin is already damaged, and we still have a struggle ahead of us (Aaron - FGD1, male, LL rural).*

Furthermore, some participants complained of the long journey they must embark on when going to the health facilities that provide skin care services. These facilities are in major hospitals within the cities while many PWAs live in rural areas. The health facilities within their rural communities do not provide qualified dermatologists. As a result, most of the time they are referred to the major central hospitals for further treatment. They are required to visit these specialized skin clinics every month to undergo a routine skin review to detect early signs of skin cancer. This increases the transport expenditure of the already vulnerable and poor individuals. The participants said:

*When I am in the village, it's difficult to get access to the hospital due to the long distance between my home and the central hospital (Sara - FGD3, KAPRA, LL Urban).*

Persons with albinism are characterized by the absence of pigment in any or all of the skin, hair and eyes; a condition which result in skin disorders, skin cancer and skin damage (Reimer-Kirkham et al., 2019). The findings of this study have confirmed that PWAs need special skin care to keep their skin in good condition and to be able to live a normal life in the scorching sun (McBride and Leppard, 2002; Registered Nurses Association of Ontario, 2012). Studies have shown that due to the plight of PWAs, many end up becoming poor and live a deplorable life (Nathalie, 2003; Masanja and Magembe, 2015). In view of this, many PWAs are unable to purchase essential body creams and medications required to keep them in good condition. People with albinism are at risk in low-income countries because of conflicting exclusionary mechanisms. Public services and essential infrastructure like hospitals are underdeveloped in these countries. In comparison to developed countries, low-income countries' health-care systems are underfunded and have less healthcare professionals who specialize in albinism (Hong et al., 2006).

### 3.9. Emotional issues

Participants expressed their fear as a result of the recent wave of violent deaths in the region. They revealed that it is becoming increasingly difficult to feel secure and trust others, as some of the victims were handed over to the killers by their own relatives. Before their albinism was brought to the forefront by the media, some participants in the focus group discussions said they survived and lived normal lives like everyone else in their culture. Some participants expressed:

*I am now 60 years and growing up in my village, I did not hear about the killings or face any challenges. I grew up and lived my life as normal as anyone else but now I live in fear of being killed (Mary - FGD2, female, LL rural).*

Participants said that the killings have brought fear and anxiety to the families of persons with albinism. Families are not at peace, especially when there is news of more killings. The participants reiterated that their parents and relatives have become worried, especially when they are not around and phone calls go unanswered. An account of one participant:

*My parents have to embrace courage when they see a police vehicle passing by our house or when they see new faces in the community. It's like 'Are they bringing bad news to them or are these new faces the so-called criminals preying on my children?' (Sandra - FGD3, female, KAPRA, LL Urban).*

The study established that persons with albinism sometimes experience a fear of the unknown in a new environment due to loneliness. This was evidenced when one of the key informants said the following:

*The first few days when a person with albinism joins the school, they are very afraid and not comfortable in a new environment. They are usually stressed and nervous about everything that is taking place. They also frequently get sick as a result of the fear that they experience (Key Informant 3 -MCM).*

Some of the participants mentioned that they experience bitterness because they have albinism. Some expressed suicidal thoughts due to the struggle they experience:

*I have bitterness in my heart and I cannot pretend that all is well with me, despite the love my parents show me. At times, I feel like I should just end my life (Saul - FGD3, male, KAPRA – LL urban).*

Due to the birth of children with albinism, some female participants experienced marital dysfunction. Abandonment, rejection, and insults were common outcomes of most births. The participants indicated that in the majority of cases, the women were left to care for the child with albinism on their own. Some fathers of albino children left their homes for other women and never returned to take responsibility for their children's care:

*When my husband saw that I had delivered a child with albinism, he abandoned me in the hospital. When I was discharged, he packed his clothes and left the house for good. He doesn't care about me and the children. All of this happened because of my white skin color (Love more - Individual Interview).*

Another participant said that her marriage was badly affected because of the media coverage of persons with albinism. The media introduced some of the myths on persons with albinism that were not known to many people in Malawi. She further stated that when her husband learnt from the media that the close relatives of persons with albinism were always picked by the police for interrogation and others jailed in the case of a killing, he became fearful and abandoned her. The participant revealed that:

*... My spouse was too afraid of being accused of conniving with the thugs, so he left (Rose- FGD2, female, LL rural).*

Another female participant mentioned that she has put on hold the desire to get married because she is afraid of being killed. She stated that:

*... With the current death threats, I don't think of getting married anymore. I am always afraid that men may not come with the intention of loving me but rather to harm me... (Sandra - FGD3, female, KAPRA, LL Urban).*

Participants, their families, and community members in Malawi were all terrified by the killings. People with albinism said they had lost faith in both their family and their community. This study confirms that stigmatization and discrimination affect the psychological wellbeing of people living with albinism in Africa (Ojedokun, 2018). Some of the participants chose not to marry because of the killings. The social well-being of people with albinism and those around them was affected by this conundrum. This is in line with Ndirangu (2014) results, which showed that some of the psychosocial problems that people with albinism face manifest themselves through the marriage institution. Owing to myths and prejudices compounded by a culture that does not fully comprehend their circumstance, some people find it challenging to establish a stable marriage.

### 3.10. Limitation

Despite the fact that this study sought to examine the problems faced by PWAs, it was unable to explore the various types of violence perpetrated against them in depth. Future research should look at the degree of violence faced by people with albinism, as this study has some limitations.

## 4. Conclusion

People with albinism suffer socially as a result of misconceptions, behaviours, social isolation, labelling, and beliefs that are negatively correlated with their disorder. PWAs face these problems as a result of public misunderstanding about albinism. People with albinism face

stigma and discrimination in society, and as a result, they are unable to obtain a proper formal education, leaving many of them without the skills needed for formal jobs. Many PWAs in rural areas are peasant farmers who have been made unproductive by the scorching sun. The inference is that these obstacles have made PWAs unable to function, forcing them to live in poverty. Their wellbeing has declined as a result of their inability to afford body creams and medical services. Additionally, people with albinism experience psychological distress as a result of the fear of being killed, as well as emotional stress as a result of social inequality. Despite the government of Malawi and some organizations such as APAM and Tiritonse commitments to address the needs of people with albinism, the assistance offered was found to be inadequate.

## 5. Recommendations

Based on the results of this research, we suggest that the Malawian government consider empowering PWAs by implementing special adult literacy classes for persons with albinism to learn how to read and write. Regardless of their academic credentials, vocational training centers should be permitted to teach them practical and hands-on skills. Furthermore, because of their poverty in society, PWAs' health-care needs should be met by a national health insurance program. Malawi's government, in collaboration with the media, should beef up public awareness campaigns to educate people about popular misconceptions about PWAs, their health needs, and their human rights. The government of Malawi, APAM, and local nongovernmental organizations that champion the needs of PWAs like Tiritonse should work together to implement these programs. These ideas will help PWAs limit the challenges that keep them from integrating into society.

## Declarations

### Author contribution statement

Thandiwe Tambala-Kaliati, Emmanuel Brenyah Adomako, Kwabena Frimpong-Manso: Conceived and designed the experiments; Performed the experiments; Analyzed and interpreted the data; Contributed reagents, materials, analysis tools or data; Wrote the paper.

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### Data availability statement

Data will be made available on request.

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The authors declare no conflict of interest.

### Additional information

No additional information is available for this paper.

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