


Exploring the experiences of persons living with albinism in Ghana

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ABSTRACT

Albinism is typically misunderstood, resulting in myths and misconceptions about the condition in different parts of the world. This study explores the misconceptions about albinism in Ghana through the lens of lived experiences of persons living with albinism (PLWA) and other relevant stakeholders to ascertain the level of socio-cultural exclusion. This study used qualitative methods and a purposeful non-probability sampling strategy was employed to gather diverse perspectives of information from participants in this study. The participants with albinism, their families, and experts were interviewed in semi-structured street interviews about their lives and the impacts of albinism on their human rights. The results revealed the extent of the suffering and denials experienced by persons living with albinism in different communities in Ghana. It reveals that due to certain misconceptions many PLWA were denied access to education, brutalised, killed, some lost their source of livelihood, and dehumanised. The study recommends that the government should organise intensive public education and health awareness in collaboration with civil society organisations to demystify albinism and promote the human rights of PLWA in Africa and Ghana in particular.

ARTICLE HISTORY

Received 17 January 2023
Revised 8 March 2024
Accepted 17 March 2024

KEYWORDS

People with albinism; social exclusion; lived experiences; myths; well-being; Ghana

REVIEWING EDITOR

John Lee, Education
University of Hong Kong,
Hong Kong

SUBJECTS

Mental Health;
Education–Social Sciences;
Religion; Indigenous
Religions; History;
Archaeology; Cultural
Studies; Health Conditions

Introduction

The condition referred to as albinism is caused by the lack of melanin pigment production in the skin (Costin & Hearing, 2007). According to Brocco (2016, p. 229), the ‘major health issues affecting people with albinism (PWA) include skin cancer, nystagmus (involuntary eye movement), photophobia and poor eyesight’. This means albinism is present at birth with little or no pigment in the skin, hair, or eyes. According to the United Nations Independent Expert on the Enjoyment of Human Rights by Persons with Albinism (UNIEA), the condition ‘albinism’ is relatively rare, non-contagious, and genetically inherited (Adonai StudiosGH, 2020a; Bradbury-Jones et al., 2018; Ojilere & Saleh, 2019). The genetic inheritance of recessive genes from both parents results in little to no melanin (pigment) production in any or all the hair, skin, and eyes (Grønskov et al., 2007). Although found in all population groups (Okulicz et al., 2003; Sajid et al., 2021), it has a relatively high frequency in sub-Saharan Africa. Research indicates that oculocutaneous albinism (OCA) is the most common type of albinism found in Africa (Baker et al., 2010; Hong et al., 2006). The physical appearance of PWA makes them stand out within the general African population. Persons living with albinism (PLWA) have pale or whitish-pink skin, and yellowish or light blond to brown hair colour (Bradbury-Jones et al., 2018; Lekalakala et al., 2015; NOAH, 2021).

Due to little or no melanin in the eyes, PLWA develops eye conditions, such as nystagmus, strabismus, photophobia, and astigmatism, leading to reduced visual acuity (Marçon & Maia, 2019). Similarly, melanin deficiency in the skin means a lack of natural protection against the sun’s ultraviolet (UV) rays. Sun exposure leads to skin conditions, such as sunburns, photo ageing, skin lesions, and skin cancer.

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According to Saka et al. (2019), about 95.2% of PLWA have skin lesions, and 11.8% present various stages of skin cancer. Skin cancer has been identified as the primary cause of morbidity and mortality among PLWA in Africa due to high exposure to UV rays (Emadi et al., 2017). Albinism is present within all ethnic groups and populations worldwide, but prevalence rates are particularly high in Africa (Brocco, 2016; Cruz-Inigo et al., 2011). Despite these, research on the lived experience of albinos has been few and far between. Therefore, it is important to conduct studies examining the experiences of PWA who may be exposed to discrimination and targeted violence within their community due to their disability status (Aborisade, 2021; Benyah, 2023). While the prevalence of people with OCA is about 1:37,000 in the US and 1:20,000 in other regions of the world (Brocco, 2016; Cruz-Inigo et al., 2011, p. 79), the prevalence in Ghana and most parts of sub-Saharan Africa is far <1:5000. There is a mammoth of evidence about how PWA are exposed to stigma all around the world, in the United States (Wan, 2003) particularly in Africa (Aborisade, 2021; Benyah, 2023; Brocco, 2016).

Daily, PLWA face jeers, taunts, and glares as they go about their daily activities in public (Brocco, 2016; Muganiwa, 2020). In Tanzania, local superstition holds that the bones, hair, and other body parts of a person with albinism can be used in potions believed to be magical for success in finding things, such as in mining (Brocco, 2016). The killings of PLWA were brought to the limelight by a Tanzanian journalist in 2008 (Burke et al., 2014; Ojilere & Saleh, 2019). The report emphasises that the human rights issue should be addressed to protect the rights of PLWA, and proffer strategies for responding to such violence (Malik et al., 2021; Ojilere & Saleh, 2019). A study indicates that PLWA in Ghana is at high risk of developing mental health complications due to discrimination, stigma, and marginalisation (Affram et al., 2019; David, 2013; Kiluwa et al., 2022). It is considered a misfortune, in some African countries to give birth to albinos; therefore, attempts are made to kill them at birth or banish them from the community (Aborisade, 2021; Benyah, 2017; Cruz-Inigo et al., 2011). However, despite the outcry over the killings of PWA in Ghana and other parts of Africa, few scholars and journalists have thus far focused on the everyday life experiences of PWA, their families, and the community contexts in which they live but there are available pieces of evidence about myths, stigma, and discriminations regarding the condition (Benyah, 2023; Brocco, 2016; Ojilere & Saleh, 2019).

This study was premised on the social injustice theory which refers to wrongful actions against individuals within society (Levy, 2019). Some of the resultant implications of the misconception and beliefs about albinism are human rights and social exclusion in nature. According to Levy (2019), injustices in society can manifest in different areas of social life, including the workplace, the education system, and the criminal justice system. Some of the examples of social injustice, some of which are human rights issues include employment discrimination, educational inequality, health care disenfranchisement, violence, social exclusion, and others (Benyah, 2023; Bufacchi, 2012). This occurs when the unequal gets treated equally while the equal gets treated unequally (Durojaye & Owoeye, 2017). The people who are most susceptible to it are minorities and oppressed social groups, including people already suffering from poverty, ethnic minorities, and the vulnerable (Cinnamon, 2017). Social exclusion (Haudenhuyse, 2017) in this regard could be seen as a breakdown of social systems; social, economic, institutional, and territorial. It could be conceived of in terms of individuals, groups, or society, in this case, PLWA who are excluded or marginalized in areas, such as education, employment, health, housing, denial or lack of friendship and community support due to cultural beliefs and misconceptions in the society (Arnold, 2010; Benyah, 2023). Even though certain rights are entrenched in certain constitutions as fundamental (freedom of speech, access to education, access to health care, human dignity, justice, and others), most times condoned when violated (Beitz, 2009; Benyah, 2023; Franklin et al., 2018).

The social exclusion of PLWA in these areas of social life is reinforced by socially constructed notions of humanness and religio-cultural beliefs, myths, misconceptions, and superstitions and how these contribute to their well-being in Ghana (Benyah, 2023). A convergence between the oppressor and the oppressed was explored in this study to find a possible amicable solution to resolving the social issue. Based on the previous studies, and a compilation of lived experiences, we examine these myths and trace their impact on the lives of PWA. There are very few articles on the lived experiences of PLWA in Ghana and many did not capture the personal and professional experiences of any person with albinism. A first-hand account of PWA, especially from one of the authors in this study, provided a deeper understanding of the nature of socio-cultural trauma experienced by the group daily. This study suggests

ways in which the myths that have surrounded PWA, which frequently have very negative undertones, can be tested by a more scientific and culturally unbiased explanation.

Materials and methods

This study used a qualitative descriptive design with purposive sampling and voluntary participation to investigate the challenges faced by PWA in the study area (Creswell, 2013). This study recruited participants who had a range of different experiences, beliefs, and attitudes on the topic area. It reviewed the viewpoints of a total of 40 participants from a purposive non-probabilistic sampling using a semi-structured interview, 39 randomised interviews, and the lived experience of one of the authors. A range of informants took part, including PWA (20), parents (12), and people with expert and professional (7) insights regarding the issue (medical doctors, activists, and human rights lawyers). This study was carried out in five villages (Atebubu, Abease, Nabu, Bukuruwa, and Akwamufie) from three districts (Oti, Atebubu-Amantin, and Bono East) and on the streets of Accra in November 2021. The participants comprised 17 females and 23 males who were at least 18 years while the oldest was 59 years. Most of the participants are out of school and not employed (22), few are in some type of employment (11), and very few are in school (7). The religious beliefs of the participants are mostly Christianity (75%), some are Muslims (16%) while traditional and others (9%) are present as well. Most of the participants were never-married singles (25/40), while the majority of the married had fellow albinos as spouses (9/15). The highest frequency of the participants was unemployed (29/40), despite being eligible to work, as only (14/40) were still in school at the time of data collection. Many of the respondents working are engaged in farming, agricultural products, and artisan businesses. Some secondary data including video recordings from social media, documents containing relevant information, and newspaper reports on certain incidences were collected.

Although many participants willingly permitted that their real names be used in dissemination and did not want numbers, codes, or pseudonyms, we cautiously used pseudonyms for some to protect individuals for respect local norms, values, and privileged safety. One of the authors was an exception in this regard, who contributed his lived experience to drive home certain relatable points in this study. Questions on daily lived experience were asked from all the categories of participants. Data was collected using both English and local languages (Akan, Ewe, Ga, Dagaare, and Dagbani), spoken in the study area, which the researcher also speaks, to allow the participants to feel comfortable. Some of the interviews were recorded using mobile phones while others were captured in the questionnaires provided. Thematic contents analysis was used to extract relevant information from the collected data and grouped it into the identified themes. Some of the comments were expressed as verbatim quotations under the presented results. The results of the analysis were presented on the identified themes. Ethical consideration permission was received from the Ethics Committee of the University of Venda, South Africa (Žukauskas et al., 2018) and informed consent was used to ascertain voluntary participation of individuals using pseudonyms to protect individuals in the project and the freedom to exit the project at any point was emphasised to participants (Mouton, 2008).

Results and discussion

The results of this study were discussed under the following themes which were identified during the analysis.

Myths, misconceptions, and beliefs about PLWA in Ghana

Ghanaians have various myths, perceptions, and beliefs about albinism depending on their traditional, customary, and cultural practices (Affram et al., 2019; Benyah, 2023; Brocco, 2016). The study revealed that in some communities, PLWA is perceived as a curse or a form of punishment from the gods for a wrong done by the family, while others tabooed their presence due to the existence of a god or deity in the community. Other communities perceive them as sacrificial lambs destined to bring good omens

to the community or for cleansing purposes (Affram et al., 2019). One of the participants, a female person with albinism said:

For instance, in 'Nabu', a small farming community in the Oti region of Ghana, PLWA is believed to prevent rainfall. As a result, people like us are not welcomed into the community and children born with the condition are killed immediately to prevent famine due to lack of rain.

This finding corroborated the study conducted by the Ghana Association of Persons with Albinism (GAPA) in three communities, namely Abease, Bukuruwa, and Akwamufie, which revealed that PLWA is not permitted to reside in each of these communities due to customary practices linked to the existence of gods and river goddesses (ENA, 2020; GAPA, 2019). In an interview with traditional leaders of Akwamufie and Bukuruwa the researcher revealed that in the past, PLWA had been sacrificed to the gods to cleanse the community as corroborated by Hong et al. (2006). Subsequently, PLWA were barred from residing or staying overnight in these communities or going close to the Chief's palace, where the shrines of the gods are located (GAPA, 2019). This experience was like that of Adonai StudiosGH (2020b), who produced a video on 2 June 2019, where a delegation of six PLWA from GAPA included one of the researchers of this paper. They embarked on a journey to sensitise and dialogue with the Chiefs and people of Akwamufie upon invitation by the Queen Mother and the Assembly member of the community. However, upon arrival in the community with a Police escort, the delegation was restricted from disembarking the vehicle close to the palace. The delegation was subsequently moved to the community durbar ground, where the event was scheduled to take place. However, the delegation was denied the opportunity to engage with the community after several deliberations between the Chiefs, the police, and the association's secretary.

This incident corroborated the ordeal narrated by NK (real name withheld) of what happened in 2010 in the same community. NK, a person with albinism, who attended a funeral in the community, was warned to leave the community on four occasions during the ceremony because his type is barred from entering the community (UTSS, 2015). As a result of these warnings, he had to hide in a bus for several hours to avoid being attacked. Their reason was that the community deity 'Tutu Abu' abhors the presence of PLWA near its shrine (Affram et al., 2019; GAPA, 2019). However, PLWA is allowed into the community but cannot stay overnight or go close to the Chief's palace where the shrine of the deity is situated.

Similarly, in 'Abease', a farming community in the Bono East region of Ghana, it is believed that sacrificing a person with albinism brings a bumper harvest to the community. In 2015, AAW (real name withheld) narrated how he nearly got offered to the deity 'Ajokrofi'. He narrated (Akoyam, 2015):

I saw a lot of people coming to our house. I heard them saying that we thank God, this year the harvest will be very plentiful, this year will have a lot of harvesting, anytime we have an albino to sacrifice to the gods, we get a lot of harvests that year. We thank God we have had one and this one is very energetic and very healthy... referring to me.

In another instance, PLWA were allowed into the Chief's palace at Bukuruwa; however, a ram was sacrificed to cleanse the palace a day after their visit. In this instance, the Chief linguist of Bukuruwa maintained that though the practice of not allowing PLWA into the community remained a tradition, they are ready and willing to engage state authorities in a possible cultural reform.

Another male participant, YF (real name withheld), narrated a story about the existence of a shrine called *Aduabone* shrine that abhors the presence of PLWA in Atebubu village. He said he was part of the delegation of PLWA that visited the village in 2020 and was prevented from entering the shrine, further confirming the existence of the belief. He further said engagement with the Chief Priest and the elders of the shrine indicated that PLWA is tabooed to live in the area, and a child born with the condition is immediately killed or banished from the community. He also confirmed that body parts of PLWA, including hair and clothes, can be purchased in the Atebubu market. YF's experience and the confession by the Chief Priest and elders of the *Aduabone* shrine were corroborated by HF (real name withheld) another female participant in this research. HF, whose father was a teacher in Atebubu, had to flee the community after she (HF) was born with the condition (Houdek, 2019). HF's parents were given the option by the traditional authorities of Atebubu to either leave the community or have their child with albinism killed (GhanaWeb, 2015).

Aside from the above beliefs and practices targeted at PLWA because of their condition, they are seen in certain instances as supernatural beings possessing spiritual powers or are considered incomplete humans. These beliefs and myths reflect derogatory names, tags, and labelling put on these individuals. For example, the common name for PLWA in the Akan language is ‘*ofri*’, meaning borrowed or a person in borrowed skin. They are called ‘*gesoshi*’ among the Ewes, which means ‘fallen from the sky’. The name *gesoshi* suggests that PLWA are not born but fell from the sky, making them supernatural beings. Among the Ewes, PLWA is also popularly called ‘*yevu*’, meaning ‘white person’ or ‘being black in white skin’ (Phatoli et al., 2015), and in most cases, the term *yevu* is added to their given names. Other derogatory names include *agbelimoyevu*—meaning cassava dough white persons among the Ewes and *gbangu* among the Dagati people. For example, my name *Kwame* (one of the researchers in this study) became *Kwameyevu* (Kwame the white person) in my village.

Moreover, it is believed that PLWA does not defecate on Fridays, does not die but vanishes, and having sex with women with albinism cures HIV/AIDS, among others (Kiluwa et al., 2022). The belief that PLWA does not die but vanish is robust to the extent that an obituary poster of a lady with albinism attracted residents of Kadjebi who were seen in groups catching glimpses of the said poster on a wall in the community (Antwi, 2018). It is also believed that pregnant women who associate with PLWA give birth to children with the condition. This belief confirmed what Baker et al. (2010) found among the people of Venda in the northern part of South Africa. According to the study, a traditional belief in snakes as spirits monitoring pregnancies could cause a child to be born with albinism. The study explained that the snake turns away from such pregnancy or the pregnant woman’s association with a person with albinism makes the snake turn the child into albinism (Baker et al., 2010).

These myths, beliefs, prejudices, and misconceptions about albinism have profound negative implications on the general well-being of PLWA, such as discrimination, stigma, and marginalisation. Due to the colour of their skin, some people even harbour the belief that PLWA is carrying and spreading the COVID-19 disease (Kossoff, 2020). As a result, PLWA has been tagged ‘Coronavirus’, increasing their vulnerability to attack, discrimination, and stigma (GhanaWeb, 2015). According to Kwame:

I faced COVID-19 related stigma thrice. In the first instance, I was tagged ‘Mr Coronavirus Man’ one evening when I was on an errand within my neighbourhood. In the second instance, I was asked, ‘Are you Chinese?’ when I was washing my hands in front of a small grocery shop in March 2020, implying that I was carrying and spreading the disease because of my skin colour, which is like that of a Chinese since the disease is believed to have originated from China. In the other instance, the driver of the vehicle I was aboard was asked by a motorcycle rider to drop me off to avoid spreading the disease to others onboard.

Kwame continues:

I have encountered several situations of people refusing to sit close to me in public transport, in other instances, mothers use me to scare their children, and derogatory remarks, jeers, and taunts are daily encounters once I step out of the house into the public space.

The complex nature of the social perception surrounding albinism in Ghana can be described as a state of in-between-ness, namely, they are often perceived as not black or melanated enough, not white enough, too white, too blind, not blind enough, having multiple disabilities, having no disabilities, or not disabled enough (UNGA, 2021). For example, said Kwame: ‘Five years ago, I found it very difficult to express myself and mostly stayed indoors to avoid taunts, jeers, and unnecessary stares’. However, even this coping mechanism creates stress, loneliness, and depression, contributing to mental health issues among PLWA (Kiluwa et al., 2022; Muganiwa, 2020). The research conducted by Affram and others revealed that PLWA is at high risk of developing mental health issues due to discrimination, stigma, marginalisation, and social exclusion they encounter in their communities (Affram et al., 2019; Benyah, 2023; Kiluwa et al., 2022). The situations described above created a barrier for PLWA to live fulfilled and meaningful lives. Until recently, PLWA did not have a voice, which has affected their participation in all aspects of life, including political, social, economic, civic, and cultural life.

Albinism and access to education

The study revealed that PLWA is denied access to education and residence due to these harmful practices. Some of the participants in this study said they went through elementary education while others

obtained tertiary education but most of them dropped out either due to bullying and discrimination or due to poverty in their households. One of the participants in the study (YF, real name withheld) narrated that in 2015, as a 17-year-old Senior High School (SHS) student living with albinism, was denied residency in Atebubu, a community in Atebubu-Amantin Municipality of the Bono East region of Ghana. YF, who gained admission into the Atebubu Senior High School as a day student, rented an apartment in the said community to stay close to the school. Upon realising his stay in the community, the Traditional Leaders of Atebubu approached YF's landlord to evict him from the house and, by extension, the community because of a belief that barred PLWA from residing within the community. Insisting on the right to education and residency of the boy by GAPA led to a stern warning from the traditional leaders stating that:

If they insist it is his fundamental human right to access education and reside anywhere, then it could happen that one day the parents would meet in an empty room (meaning he would be kidnapped and killed), without knowing who to ask or blame of the whereabouts of their son.

The exclusion of PLWA of this nature is very common in Ghana. The situations described above barricaded access to adequate social services and Economic Social and Cultural Rights (ESCR) by PLWA, resulting in this population's poor standard of living and social status in society (GhanaWeb, 2015). According to the Committee on Economic, Social, and Cultural Rights (CESCR), education is both a human right and an indispensable means of realising other human rights (CESCR, 2013). Education is an empowerment right that can lift economically and socially marginalised individuals from poverty (Affram et al., 2019; Franklin et al., 2018).

The study revealed that PLWA has varying degrees of low vision due to reduced or zero melanin production in the eye. The low vision means they cannot see clearly from afar, impairing their access to information in the classroom. The lack of melanin leads to nystagmus, photophobia, and strabismus, resulting in reduced visual acuity in this population (Brocco, 2016). Access to education is negatively impacted when there is a lack of reasonable accommodation, for example, large print textbooks and other assistive devices and technology (Ero et al., 2021). It is important to note that Ghana has an inclusive education policy; however, its effective and efficient implementation is marred by several infrastructural and resource challenges. The finding in this study that teachers lack adequate training and resources to effectively implement the policy to benefit persons with disabilities, including albinism, in their classrooms was corroborated by Ocloo and Subbey (2008).

Some of the participants mentioned that aside from teachers' unwillingness or unawareness of the needs of students with albinism, children with albinism in schools also face discrimination, bullying, and labelling by their peers and teachers alike. In addition, other students refuse to play with children with albinism on parents' instruction or based on pre-existing prejudices and misconceptions associated with the condition. One of the parents of a pupil with albinism said:

For instance, a class teacher maltreated my five-year-old boy with albinism because of the belief that getting close to the boy would cause her to give birth to a child with albinism.

The low academic performance, repetition of classes, and subsequent academic progression among PWA in the study area could be attributed to some of the above-mentioned problems. The combined effects of these factors lead to high dropout rates and low performance among PLWA reducing their chances of an adequate standard of living and participation in political, social, economic, and cultural life in their communities (Adonai StudiosGH, 2020a). The experience is a massive exclusion in every sphere of life. One participant said:

The situation is even worse in remote areas generally due to a lack of adequate infrastructure such as classroom blocks, teaching and learning material and assistive devices. In addition, large class sizes mean students with special learning needs receive no individualised support from teachers.

Aborisade (2021, p. 8) confirms the above finding when he said the father of a PWA dropped his child from school because he had doubts about the child being employed because of his condition. Furthermore, the lack of reasonable accommodation and discriminatory attitudes exhibited by other students and teachers alike challenge the learning capabilities of students with albinism, further contributing to low self-esteem and diminished life ambitions (Benyah, 2017; UNGA, 2021).

Access to healthcare

Access to adequate healthcare by PLWA is crucial to their survival, especially in Ghana, where daily sunshine ranges between 6 and 7 hours. Due to the lack of melanin in their skin and eyes, PLWA is predisposed to the harmful effects of the UV rays from the sun (Emadi et al., 2017; Marçon & Maia, 2019). A possible solution to this harmful effect is to get skin shields or anti-UV creams but some of them are very expensive and out of reach to many PLWA. The World Health Organisation (WHO) defines health as a state of complete physical, mental, and social well-being and not merely the absence of disease or infirmity (Kiluwa et al., 2022; Grad). The WHO further emphasised that health is one of the fundamental rights of everyone, including PLWA, without distinction of race, religion, political belief, economic or social condition (Grad). A participant, a PWA with a medical background said:

The exposure to sun increases their susceptibility to skin damage and eye problems. Excessive sun exposure results in sunburns, rashes, premature photo-ageing, wrinkling, and skin lesions. Skin lesions left untreated develop into skin cancer among PLWA.

Studies have revealed that skin cancer is mostly caused by exposure to excessive UV rays among PLWA in Africa (Lund & Taylor, 2008). Though there is a dearth of research data on the prevalence rate of skin cancer among PLWA in Ghana, a recent study in neighbouring Togo indicated a 95.2% rate of skin lesions among PLWA with an 11.8% incidence rate of skin cancer (Saka et al., 2019). The study of 64 cases of skin cancer in patients with albinism at a hospital in Tanzania found that most (84%) were under the age of 40 years, with 8% as young as 11–20 years of age (Bradbury-Jones et al., 2018). There are no cures for any kind of cancer, but there are treatments that may give them more time or even more years to live. The cost of medical treatments is very expensive and unaffordable for the PLWA. It is well known that this is a major disease that affects the PLWA, yet there is no known intervention by the government to provide necessary healthcare support for the group.

According to Smith-Asante (2018), currently, Ghana can only boast of 23 dermatologists serving over 30 million people, and most of them are in urban areas, such as Accra and Kumasi. This means access to dermatological services by PLWA is challenging, especially for those in remote areas whose daily survival needs depend on farming and other outdoor activities. Furthermore, Ghana has only three cancer treatment facilities, Korle-Bu and Komfo Anokye Teaching Hospitals and a privately owned Sweden-Ghana Medical Center (Fiagbedzi & Ahadzie, 2004). These three facilities are in Accra and Kumasi, with a heavy backlog of patients waiting to be treated. Therefore, accessing these facilities becomes challenging for PLWA due to travel time, financial resources, and waiting time to receive treatment. In the first place, most families of PLWA cannot afford the cost of long-distance travel to Accra or Kumasi and the cost of the treatment. Secondly, those who can afford these expenses have to wait for a long time to get treated, resulting in further spreading or growth of the cancer tumours. A participant revealed that:

A 16-year-old boy with advanced-stage forehead cancer had to be transported from Nalerigu to Accra, about 660 km or 13 hours of travel time. This happened because there was no treatment facility within that part of the country. Further engagements with the boy's family indicated that he has been undergoing treatment in a Polyclinic at Nalerigu. However, his wound was treated as a common skin problem without any lab investigation leading to further cancer growth.

Similarly, a participant narrated the case of her family member called CA (real name withheld), a skin cancer patient with albinism, who had to delay his treatment because of the COVID-19 pandemic strain on health facilities. As a result, his situation worsened, and the cancer spread further to his internal organs, reducing his chances of surviving the treatment. CA was initially diagnosed to receive radiotherapy treatment, but due to the delay that led to the disease's spreading, chemotherapy was added to the treatment plan, increasing the cost of treatment while leaving him with a slim chance of survival. Sadly, others lose their lives to the disease due to financial problems or long waiting times. Unfortunately, sunscreen is a luxury and can only be found in Supermarkets and malls at an exorbitant price. This essential product is out of reach to the ordinary PLWA in Ghana. PLWA cannot access healthcare services, especially treatment for skin cancer, due to poverty and lack of government support (Kiluwa et al., 2022; Thompson-Hernández, 2018). The National Health Insurance Scheme (NHIS) does not cover skin cancer treatment, and the provision of visual aids is considered an exclusion from the benefits

package of the scheme (NHIS, 2015). For instance, CA was said to rely on the media to raise enough funds to undergo radiotherapy and chemotherapy procedures to treat himself as there are no clear-cut policies on albinism in Ghana (News360, 2021).

Quality of service delivery to PLWA is low due to their appearance, which some health workers find very repugnant. Another participant narrated the story of a 23-year-old man with albinism who was left to die due to the offensive odour caused by an advanced-stage tumour. Attitudes of some health workers towards PLWA are influenced by societal prejudices, resulting in low service delivery to these individuals at the health facilities. A respondent who was a mother of a baby born with albinism at the Tema General Hospital was mocked by nurses, which led to the dejection of the baby by the mother. She said:

My husband because of the incident subsequently abandoned me and the baby because of the skin colour of the boy. I refused to breastfeed him for some days due to the nurses' reactions.

This incidence indicates the societal pressure exerted on parents of children with albinism which subsequently influences the health of these young ones. In these cases, parents tend not to care for their children with albinism (Adonai StudiosGH, 2020a, 2020b). Factors, such as inadequate personnel, lack of knowledge on skin cancer by health personnel and PWA alike, late presentation of skin cancer cases at health facilities (Kiluwa et al., 2022; Vanderpuye & Aryeetey, 2016), and inadequate healthcare facilities, goods, and services worsen the enjoyment of the right to health by PLWA in Ghana. The health sector in Ghana and many African countries are in shambles hence adequate and special health care is a mirage to PWA. According to the findings in this study, these have led to the untimely death of many PLWA and the healthcare facilities should be improved to end death among this group of people.

Access to work and employment opportunities

The study revealed that due to myths and misconceptions surrounding albinism, many employers or potential employers shy away from engaging in the services of PLWA. At the same time, others fear losing potential customers because of their presence (Benyah, 2023; Brocco, 2016). Many of the participants in the study who are PWA, especially the females are not employed even though some of them qualify for jobs. Many believe that PLWA does not have the requisite skills to perform on the job. A few are engaged in menial jobs and farming. This finding is similar to that of Emadi et al. (2017) who said access to work, or employment opportunities remains a challenge for PLWA in Ghana primarily because of their skin condition and barriers to accessing education (Franklin et al., 2018). Furthermore, the belief that PLWA is cursed prevents others from associating with them (Benyah, 2017). As a result, potential employers fear engaging their services as they would only be liabilities for scaring away potential customers rather than contributing positively to the organisation's growth. Some participants said they could not do certain jobs due to their condition and the fear of being attacked.

Furthermore, PLWA who are entrepreneurial also find it challenging to keep their businesses afloat due to stigma and discrimination. The belief that PLWA is cursed, or bad luck deters potential customers from patronising their businesses (Adonai StudiosGH, 2020b). One of the respondents said:

It was difficult for people to buy food from PLWA. These situations leave us with no choice but to engage in outdoor activities such as farming and other menial work which exposes us to the sunlight to survive, even though we know it is detrimental to our health.

PLWA face several barriers in accessing education, further limiting their chances of getting employment indoors. As a result, they cannot meet various job requirements due to low education and skills (Franklin et al., 2018; Ocloo & Subbey, 2008). Moreover, there is a lack of reasonable accommodation at the workplace, especially assistive technology, to enhance the low vision of PLWA (Affram et al., 2019).

Strategies to prevent the human rights violation of PLWA

PLWA faces a wide range of human rights violations, including discrimination, stigma, social exclusion, and even violence as a precursor to myths, misconceptions, and cultural beliefs. In some regions, particularly in parts of Africa, there have been instances of targeted killings and mutilations of people with

albinism (Ojilere & Saleh, 2019). Their body parts are believed to possess magical properties, leading to attacks by individuals seeking to use them in rituals or traditional medicine (Machoko, 2013). The Anatomy Law (2010) in Malawi prohibits the unauthorized dissection, retention, and sale of human body parts. It specifically includes provisions to protect people with albinism. PWA often face discrimination in various aspects of life, such as education, employment (Benyah, 2023; Franklin et al., 2018), and social integration. They may be denied opportunities and experience marginalization due to misconceptions and stereotypes about their abilities and appearance. The Persons with Disabilities Act (2010) in Tanzania aims to promote and protect the rights and welfare of persons with disabilities, including those with albinism (Malik et al., 2021). It prohibits discrimination and addresses issues, such as education, employment, healthcare, and accessibility (Benyah, 2023; Franklin et al., 2018). Albinism is associated with increased sensitivity to sunlight, which can lead to skin cancer and other health issues (Kiluwa et al., 2022). A study by researchers in Tanzania found that educational interventions aimed at increasing knowledge and understanding of albinism led to improved attitudes towards people with the condition (Franklin et al., 2018; Kiluwa et al., 2022). The study involved women from rural and urban areas in Tanzania, where people with albinism are at high risk of discrimination and violence (Brocco, 2015). The researchers found that participants who received the educational intervention showed significantly greater knowledge and understanding of albinism and were more likely to have positive attitudes towards people with the condition. The study highlights the importance of education and awareness-raising as a strategy to prevent the violation of PLWA (Franklin et al., 2018). However, individuals with albinism may face challenges in accessing adequate healthcare, including specialized services and affordable sunscreen.

It is worthy to note that these cultural beliefs and practices against albinos violate the fundamental human rights (Ojilere & Saleh, 2019) of PLWA in Ghana, including the rights to life, equality and freedom from discrimination, and freedom of movement as set out in chapter five of the 1992 Constitution of Ghana. Furthermore, the Constitution protects the cultural rights of everyone in article 26(1), which states; 'every person is entitled to enjoy, practise, profess, maintain and promote any culture, language, tradition or religion subject to the provisions of this constitution' while clause 2 of the same article prohibits all customary practices, which dehumanises or are injurious to the physical and mental well-being of a person (Ghana 1992, rev. 1996). Therefore, it is evident that these customary practices contravene the provisions of the Constitution, which is the supreme law of the land. Furthermore, the practices also violate various international human rights law provisions, including, among others, article 2 of the African Charter on Human and Peoples' Rights (ACHPR, 1986), articles 5, 10, 14, 15, and 19 of the United Nations Convention on the rights of persons with disabilities (UNCRPDOP, 2006), articles 5, 8, 9, 10, 11, and 14 of the Protocol to the African Charter on Human and peoples' rights on the rights of persons with disabilities in Africa (AU, 2018). Moreover, the restrictions imposed by the communities on PLWA are harmful practices targeted at these individuals because of their appearance, raising security concerns and making the population vulnerable to ritual attacks, discrimination, stigma, and social exclusion (Benyah, 2023; Muganiwa, 2020). Human Rights Council resolution on the 'Elimination of harmful practices related to accusations of witchcraft and ritual attacks' adopted in July 2021 'urges States to condemn harmful practices related to accusations of witchcraft and ritual attacks that result in human rights violations (Ojilere & Saleh, 2019; UNGA, 2021)'.

Ratification of the African Charter on the Rights and Welfare of the Child (Law No. 7/2008, 1990) in Mozambique ratified the African Charter on the Rights and the Welfare of the Child, which includes provisions to protect children with albinism from discrimination, abuse, and violence. Children and adults with albinism are sometimes subjected to bullying, teasing, and harassment due to their physical appearance. This can have severe psychological and emotional impacts on their well-being. United Nations General Assembly Resolution 69/170 (2014) condemns attacks and discrimination against persons with albinism and calls upon member states to take measures to prevent such violence, protect victims, and ensure access to justice (Benyah, 2023).

This study suggests strategies to prevent the violations of human rights against PLWA using a multi-faceted approach as follows. One of the most effective ways to prevent discrimination and violence against PWA (Benyah, 2023) is through education (Franklin et al., 2018). Raising awareness about albinism, its causes, and its effects can help to dispel myths and misconceptions about the condition and

promote greater understanding and acceptance (Benyah, 2023; Franklin et al., 2018). It is important to raise awareness, challenge stereotypes, promote inclusive policies, and ensure the protection and well-being of individuals with albinism, in line with international human rights standards. Strong laws that prohibit discrimination and violence against PLWA can be an effective tool for preventing violations (Benyah, 2017, 2023; Franklin et al., 2018). Governments should enact and enforce laws that protect the rights of PWA (Malik et al., 2021). Advocacy efforts can help to raise awareness about the challenges faced by PLWA and promote greater respect for their rights (Franklin et al., 2018). Advocates can work to change attitudes and behaviours towards PLWA and promote greater inclusion and acceptance. Governments and civil society organisations should work together to protect PWA. This can include providing security services, such as police protection and safe housing, as well as providing support for victims of violence. Access to quality healthcare is essential for PLWA, who are at increased risk of skin cancer, vision problems, and other health issues (Kiluwa et al., 2022). Governments should work to ensure that people with albinism have access to the healthcare services they need. Economic empowerment can help to reduce the vulnerability of PLWA to discrimination and violence (Benyah, 2017). Governments and civil society organisations should work to provide vocational training and other economic opportunities to PWA. By implementing these strategies, we can promote greater respect for the rights of PWA and work towards a world where they can live free from discrimination, stigma, and violence (Benyah, 2017).

Recommendations

To promote an inclusive society where PLWA live a meaningful life devoid of discrimination and stigma, public education on the condition must be intensified (Franklin et al., 2018). With the help of Civil Society, the government must organise intensive and continuous community and school-based sensitisation programmes to promote understanding of albinism. Such public education programmes must be age-appropriate and targeted toward changing attitudes and behaviour toward PLWA. Public education should include traditional authorities/rulers, faith-based organisations, traditional healers, community opinion leaders, PLWA, and their families. This study found that women and children (PLWA) are more susceptible to all manner of attacks than their male counterparts hence, a definite intervention that will prevent these evil practices should be enacted (Kiluwa et al., 2022).

Moreover, the adoption of International Albinism Awareness Day (IAAD) for commemoration as an annual national event by the National Council on Persons with Disabilities will promote awareness creation on albinism nationwide. The IAAD will serve as a national platform for deliberation on issues affecting PLWA and ways to address them. Similarly, adopting albinism awareness month during which nationwide public education activities can be organised to create a massive awareness of the condition (Franklin et al., 2018). These activities should include public lectures, seminars, workshops, and dialogue sessions at various levels of engagement for multiple sectors, including health and education (Franklin et al., 2018; Kiluwa et al., 2022). It should also incorporate capacity-building training and skills development for PLWA.

Research has shown that skin cancer kills more PLWA than ritual attacks and murders, it is essential to state that adequate sun protection measures must be followed strictly to reduce the impact of skin cancer on this population. Per their condition, which comes with multiple specialist healthcare needs, PLWA needs specialist healthcare services, such as dermatological and regular skin screening, early detection and treatment of skin problems, including skin cancer, as well as eye-related check-ups and eye care services (Kiluwa et al., 2022).

In collaboration with CSOs, the government should implement innovative public education programmes through traditional media outlets, such as radio and television to discuss albinism (Franklin et al., 2018). People are ignorant about the condition and should be conscientised. In addition, produce short films on albinism for both conventional and social media. These films should project diversity in society and promote the inclusion of albinism in every sphere of social life to eliminate discrimination and harmful cultural practices. This paper emphasises the importance of awareness creation (Franklin et al., 2018), which should be a top-down approach with leaders/government taking a leadership role to dispel all myths around albinism by appointing more PLWA into political offices. Unfortunately, little

research has been conducted around albinism itself or how PWA can improve their livelihoods and be accepted without prejudice. Hence, more research work should be done on the topic.

Conclusion

This paper shows that PLWA in Ghana live in a complicated situation where they face discrimination, stigma, marginalisation, and social exclusion in many facets due to myths, misconceptions, and cultural beliefs. It is challenging for PLWA to access education, healthcare, and employment opportunities in Ghana due to their condition and the associated belief system surrounding albinism discussed in this paper. However, access to these essentials of life remained a daunting task for PLWA in Ghana. The primary factor contributing to these situations is the lack of information on the condition, which leads to the formation of myths, misconceptions, and prejudices, fuelling the challenges facing this minority group. This study was able to broaden the understanding of PWA among integrated disability and societal systems to help in identifying and framing the barriers encountered by this group and suggest possible ways to overcome them. Some of these issues (discrimination, socio-economic exclusion, education and health deprivation, and others) have been left unattended for a long time and so putting the lives of PWA in further disenchantment. In addition, recognising the predicaments of PWA will enable this category of people to equip themselves better to ensure that their safety, coping, self-esteem, and well-being are not compromised.

Acknowledgements

We hereby acknowledge the full permission and rights given to us by individuals and organisations whose names were mentioned or used in this paper to drive home different points and provide contexts to this study on the lived experience of PLWA in Ghana and elsewhere in the world. In addition, we acknowledge every participant who shared their experiences, insights, and beliefs about albinism in this study. The views and opinions expressed in this article are those of the authors and do not necessarily reflect the official policy or position of any affiliated agency of the authors.

Disclosure statement

The author(s) have reported that there are no potential conflicts of interest.

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Andrews Kwame Daklo, mentee under the second author. He studied and completed his Master's programme in democratisation and human rights at the Centre for Human Rights, University of Pretoria. He conceptualised the study and conducted the data collection. He also shared his personal experiences in the original draft of the manuscript. He was part of the mentorship programme organised by the University of Pretoria that visits the University of Venda every year as part of the requirement for graduation from the Master's programme. Dr. Olusegun Obadire is an active researcher and mentor at the University of Venda who contributed largely to the quality of the manuscript to the level it is now. He designed the methodology, formal analysis, visualisation, project administration, validation, provided resources, supervised and reviewed and edited the manuscript.

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