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LIVING WITH ALBINISM IN GHANA: PERCEPTIONS, MYTHS AND SUPPORT SYSTEMS

BY

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DECLARATION

I hereby declare that this thesis is my own work towards the Master of Public Health degree and that, to the best of my knowledge, it contains no material previously published by another person nor material which has been accepted for the award of any other degree of the College, except where due acknowledgement has been made in the text.

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DEDICATION

I dedicate this thesis to my mother, Elizabeth Peprah, my sister Joy Peprah and the entire family.

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DEFINITION OF TERMS

Dermatology	The branch of medicine that focuses on the diagnosis, treatment, and prevention of diseases and conditions affecting the skin, hair, nails, and mucous membranes.
Disability	A physical, mental or sensory impairment which gives rise to physical, cultural or social barriers that may hinder their full and effective participation in society on an equal basis with others.
Health	A state of complete physical, mental, and social well-being, and not merely the absence of disease or infirmity
Myth	A widely held but false belief or idea.
Superstition	A widely held but irrational belief in supernatural influences, especially as leading to good or bad luck, or a practice based on such a belief.
Oculocutaneous Albinism	A genetic condition characterised by reduced or absent melanin pigment in the skin, hair, and eyes, caused by mutations in genes involved in melanin production.
Ophthalmology	The branch of medicine that focuses on the diagnosis, treatment, and prevention of diseases and disorders of the eye, visual system and related structures.

ABBREVIATIONS

AAN	Africa Albinism Network
AUPA	African Union of Persons with Albinism
COVID-19	Coronavirus Disease of 2019
ENA	Engage Now, Africa
GAPA	Ghana Association of Persons with Albinism
GDP	Gross Domestic Product
GFD	Ghana Federation of Disability Organisations
NHIA	National Health Insurance Authority
NHIS	National Health Insurance Scheme
NGO	Non-Governmental Organisation
NSS	National Service Scheme
OCA	Oculocutaneous Albinism
PWA	Person(s) with Albinism
SEM	Socioecological Model
UN	United Nations
WHO	World Health Organization

ABSTRACT

Introduction: Oculocutaneous albinism (OCA) is a genetic disorder that manifests as a reduced or absent skin, hair and eye melanin pigmentation resulting in visual, skin disorders including skin cancer and stigmatization. This contributes to the negative overall experience of Persons with Albinism (PWA). These individuals are subjected to abuse generated by unhelpful misconceptions, myths and cultural beliefs in many African communities. This study highlights the lived experiences of persons with albinism in Ghana including their unique challenges and support systems they utilise to cope with these challenges.

Methodology: The study used a qualitative research design, primarily a phenomenological approach. The target population includes persons living with albinism in the selected regions in Ghana. A purposive sampling technique was utilised to select participants. In-depth interviews and semi-structured interviews were employed. A total of 24 participants were interviewed. Thematic analysis was done using Atlas.ti software to analyse the data.

Results: This showed that participants did not view albinism negatively but accepted it as a condition despite various challenges faced. This was in contrast to the largely negative community perceptions of albinism. Participants also recounted difficulties coping with challenges such as health, educational and economic challenges that significantly affect their quality of life. There were also instances of human rights violations and real threats to the lives of PWA in some communities. Family acceptance and support play a major role in the overall well-being of PWAs.

Conclusion: Persons with albinism reported various myths and beliefs about albinism persisting in their communities. Application of the socioecological model to the perspectives of persons with albinism helps to understand the experiences of PWA in a structured manner. It provides opportunities for intervention that may be more effective and impactful. This study suggests supporting PWA may be more effective with a multi-level intervention approach.

Keywords: Albinism, Persons with albinism, lived experiences, persons with disabilities, support systems,

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Chapter 1- Introduction

1.1 Background Information

Oculocutaneous albinism (OCA) is a group of rare autosomal recessive genetic disorders that affects people all over the world. This manifests as reduced or absent skin, hair and eye melanin pigmentation (Kromberg, Flynn and Kerr, 2023). Eight subtypes of OCA have been characterised and localised to specific gene loci. The different genetic abnormalities vary based on the geographic location. Albinism affects people from all races and ethnic groups all over the world. Some communities have higher incidences that are driven by intermarriage norms, cultural norms like consanguineous marriages in these communities (Marçon and Maia, 2019).

Globally, the incidence of albinism is about 1:20,000 people. A lower rate has been recorded in regions such as the United States of America (1: 37,000), while the Cuna Indigenous people residing in Panama and Colombia in South America have a reported incidence of 6.3 per 1000 population (Marçon and Maia, 2019). In Africa, epidemiological data are varied, with a reported incidence of 1:1000 amongst the Tonga tribe of Zimbabwe to 1:15,000 in mid-eastern Nigeria. However, over the Sub-Saharan region, where Ghana is located, the incidence ranges from 1:5000 to 1:15,000 (Wright, Norval and Hertle, 2015).

The consequences of this alteration in pigmentation include visual disturbances, increased incidence of skin disorders and psychological impact of being “different” and stigmatisation experienced in many African communities (Cruz-Inigo, Ladizinski and Sethi, 2011). Although persons with albinism have different skin tones due to varying degrees of pigmentation, all are at an increased risk of skin disease, including skin cancer, following exposure to ultraviolet light or sunlight. Cutaneous problems encountered include frequent sunburns, which limit outdoor activities, freckling, nevi, lentigines and increased rate of cutaneous ageing. Common malignancies include squamous cell carcinoma and basal cell carcinoma (Ma *et al.*, 2023). The lighter skin tone of persons with albinism is also more striking among the darker-skinned people in Africa. They, therefore, stand out much more easily than Caucasians. A study conducted by Daklo and Obadire explored the experience of PWA in Ghana and found that they had limited access to education, specialised healthcare services, and employment opportunities (Daklo and Obadire, 2024). This situation contributes to the negative psychosocial experience of PWA. These individuals are stigmatised (Bradbury-Jones *et al.*, 2018), ostracised and subjected to abuse generated by unhelpful misconceptions, myths and cultural beliefs in many African communities (Franklin *et al.*, 2018).

Coping refers to the thoughts and actions carried out by individuals to deal with internal and external stressors. The term suggests voluntary actions or behaviours developed to minimise the impact of the stressful situation. Coping strategies or styles are therefore patterns of behaviour consistently utilised to address these stressors (Algorani and Gupta, 2024). Individuals often develop various strategies to cope with their situation. These may be proactive or reactive. The coping mechanisms employed by PWA have not been adequately explored.

In Ghana, persons with albinism were legally recognised as persons with disabilities following the Persons with Disability Act (Act 715) enacted in 2006. The act clarifies "person with disability" as an individual with a physical, mental or sensory impairment, including a visual, hearing or speech functional disability, which gives rise to physical, cultural or social barriers that substantially limit one or more of the major life activities of that individual (ARRANGEMENT OF SECTIONS Section Rights of persons with disability, 2006). Further solidifying that recognition, Ghana signed the UN Convention on the Rights of Persons with Disabilities (CRPD) in 2007 and ratified it in August 2012, reinforcing its legal obligations to protect and promote the rights of all persons with disabilities, including those with albinism.

The Ghana Association of Persons with Albinism is a national advocacy and support organisation that galvanises persons with albinism in Ghana to raise awareness, educate its members and the community. It also advocates for the protection of the rights of PWAs and lobbies to develop and implement policies that advance the interests of the albinism community. Some activities include organising International Albinism Awareness Day celebrations, obtaining support in the form of skin care products, protective clothing and facilitating healthcare access for its members. The structured organisation has also allowed other NGOs and government institutions to engage the albinism community and support them appropriately without fear of exploitation or abuse of persons with albinism (Dery, 2023).

In recent times, one of such NGOs is Engage Now Africa (ENA). It is an international NGO operating mainly in Sub-Saharan Africa with offices in Ghana, Ethiopia, Sierra Leone and Namibia, to fund projects that address extreme poverty and help individuals and families become self-reliant (Engage Now Africa, 2023). ENA has partnered with GAPA in an effort to address some of the challenges faced by persons with albinism in Ghana. As part of their programs, they successfully conducted various albinism sensitisation and advocacy programs in different regions in Ghana. Beyond this, the organisation has also been supportive of PWA by providing livelihood support in various forms to help improve their quality of life. These include setting up businesses, funding eye and skin treatments and funding the education of people in need of support. These interventions have been conducted from 2018 to 2024, with several people from different parts of the country benefiting from these initiatives (Advocating for People with Albinism in Ghana | Engage Now Africa, 2023). This study also seeks to identify the support systems available to PWAs and their perceptions of the support they receive from these organisations.

Notwithstanding the challenges, people living with albinism can otherwise lead normal lives with normal life expectancy. Addressing these challenges will, therefore, significantly improve their physical, social, and mental health and overall quality of life. It is therefore worthwhile to begin to address this concern by raising awareness and educating communities about albinism to demystify the phenomenon.

1.2 Problem Statement

Several myths and misconceptions concerning albinism persist, especially in Ghana and other African countries. Some of the myths include the belief that PWAs are descended from gods, are cursed or can be used for rituals. Others are absurd, such as the suggestion that they cannot die or have bad luck and therefore must be avoided. These assertions create problems for PWA and often strain their relationship with their communities. In addition to this, persons with albinism (PWA) are faced with various challenges that affect their health and also interfere with their education and subsequent employment opportunities (Adelakun and Ajayi, 2020).

The stigma and discrimination against them often lead to limited job opportunities. In addition to this, some employers also view them as being incapable or being a burden. These have been noted in many African countries, as described by Uromi in 2014. For those who are self-employed, potential customers may shun their enterprises and therefore limit their potential income and the sustainability of the business. The situation is further complicated by the fact that not all jobs are suitable for persons with albinism due to health concerns described earlier. Occupations that require prolonged periods outdoors are not ideal due to the risks of skin cancer and other cutaneous lesions following prolonged sun exposure (Benyah, 2022).

In some communities, persons with albinism a murdered and used for rituals intended for prosperity and well-being. For instance, a United Nations report suggested an increase in ritualistic murders in 2021, amidst the global COVID-19 pandemic, in the hope of obtaining wealth (Ero, 2021).

Furthermore, despite the advocacy efforts of the Ghana Association of Persons with Albinism (GAPA), there's still a lack of NHIS coverage of conditions that affect PWA. Over the years, GAPA has advocated for the inclusion of sunscreen products, visual assessment and treatment services and psychological support services into the NHIS benefit package for PWA (Setordjie, 2024). However, this has not been realised, and therefore members have to make out-of-pocket payments to access these services and obtain these products.(Daklo, 2021).

1.3 Rationale of Study

As noted above, the albinism community has been marginalised, especially in African countries. Their lived experience is unique, with multifaceted problems including threats to overall health and violation of basic human rights.

Research in this field is essential for informing strategic support initiatives and legislation that can create a more conducive and supportive environment for them to thrive in the community. This study, therefore, seeks to add to the body of knowledge concerning the experiences of PWA in Ghana and interventions targeted at this unique community. The findings from this study can form the foundation for strategies to address stigma, discrimination and health inequities experienced by the albinism community.

Noting the complex challenges, organisations such as Engage Now Africa (ENA), in collaboration with the Ghana Association on Persons with Albinism (GAPA), have carried out several projects, such as sensitisation and education programmes and livelihood support initiatives. These initiatives are intended to alleviate the challenges described and improve the living experiences of PWA (Engage Now, Africa, 2016).

The findings from this study will highlight health inequities, human rights violations and gaps in health policies that create room for the challenges of PWA to thrive. Understanding the roots of these challenges and the support available can provide valuable intelligence to develop or design public health interventions and review health policies to address these pertinent issues. Emphasising problems in educational institutions faced by PWA would also help develop policies and procedures to address these challenges.

1.4 Conceptual Framework

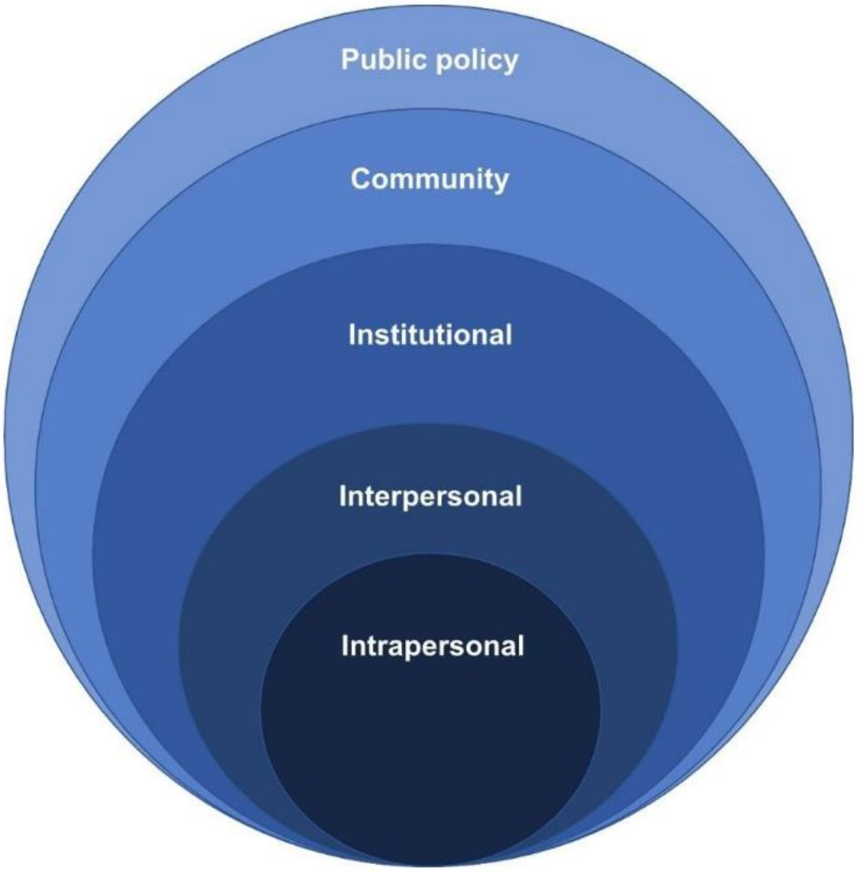

Fig. 1.1 Overview of the SEM proposed by Mcleroy and colleagues (Mcleroy et al. 1988)

The framework utilised is the socioecological model. The experience of persons with albinism can be viewed through the lens of this model. The model establishes a hierarchy of levels of influence, which are individual/intrapersonal, interpersonal, institutional, community and public policy levels. In this context, the experiences of PWAs can be explored in the following ways.

At the individual level, personal characteristics such as the degree of visual impairment, skin protection strategies, level of knowledge of albinism and response to stigma and discrimination can be discussed.

The interpersonal level highlights the relationship with family, family acceptance and support systems available to them. The interactions with peers, especially in teenage years, can have long-term effects on mental health and education.

At the institutional or organisational level, it can be represented by the role of NGOs and advocacy groups such as Engage Now Africa and GAPA. Educational institutions also play a role in developing policies to accommodate the needs of PWAs in their facilities.

Community-level influence involves the myths and beliefs held by community members concerning albinism. This determines whether a community will support or discriminate against PWA. Other important ways include access to healthcare services.

At the top level, public policies can create an enabling environment for PWAs to thrive. For example, the Persons with Disability Act (Act 715) establishes the legitimate rights of persons with disabilities, including PWAs. Although enforcement can sometimes be met with barriers.

The socioecological model, as demonstrated, can comfortably be applied in this study and provide a structure for exploring the lived experiences of persons with albinism.

1.5 Research Questions:

1. What are the common perceptions of albinism in Ghana
2. What are the challenges and barriers faced by PWA in Ghana
3. What are the support networks utilised by persons with albinism

1.6 Objectives:

The goal of this project is to examine the lived experiences of people living with albinism, their perception of albinism and support systems

1.7 Specific Objectives:

1. To describe the perceptions of albinism

2. To identify challenges and barriers encountered by persons with albinism

3. To identify support networks utilised by persons with albinism

1.8 Profile of Study Area

Ghana is a West African country bordered by Côte d'Ivoire to the west, Burkina Faso to the north, Togo to the east, and the Gulf of Guinea and the Atlantic Ocean to the south. Ghana is located on the Gulf of Guinea, a few degrees north of the Equator. It spans an area of 238,540 km2 (92,101 sq mi) and has an Atlantic coastline that stretches 560 kilometres (350 miles) on the Gulf of Guinea in the Atlantic Ocean to its south. Dodi Island and Bobowasi Island are near the south coast. It lies between latitudes 4°45'N and 11°N, and longitudes 1°15'E and 3°15'W. The prime meridian passes through Ghana, specifically through Tema. Ghana is geographically closer to the intersection of the Prime Meridian and the Equator than any other country, since this point (0°, 0°) is in the Atlantic Ocean approximately 614 km (382 mi) off the south-east coast of Ghana.

Ghana’s climate is determined largely by the interplay of two air masses: a hot, dry continental air mass that forms over the Sahara and a warm, humid maritime tropical air mass that forms over the South Atlantic. Both air masses move toward the Equator with their hemispheric winds and meet at the Guinea Coast for several months each year. Continental air moves southward with the northeast trade winds, known in western Africa as the harmattan, and maritime tropical air moves northward with the southwest trades. (Ghana Location and Size - Flags, Maps, Economy, History, Climate, Natural Resources, Current Issues, International Agreements, Population, Social Statistics, Political System, 2013).

The population is estimated to be 33 million (2024 estimate), with a high youth population (median age of about 21 years). It has diverse ethnic groups, including the Akan, Mole-Dagbani, Ewe, Ga-Dangme, forming the majority of the ethnic groups. To date, there has not been research to determine the population of persons with albinism in Ghana.

Ghana has a mixed economy, with agriculture, mining, and services as key sectors. Ghana’s GDP was estimated at $88 billion in 2023, with a per capita GDP of approximately $2,800 (Ghana Statistical Service, 2021)

Ghana’s healthcare system includes a mix of public and private providers, with the Ghana Health Service managing public health facilities. The National Health Insurance Scheme (NHIS), introduced in 2003, aims to make healthcare more affordable and accessible. Health facilities and healthcare workers are concentrated in urban areas, creating disparities in rural healthcare access.

The Ghana Association of Persons with Albinism, in partnership with organisations such as Engage Now Africa, also organises conferences where members from all over the country attend and receive eye and skin screening to identify health challenges and support them to receive the needed treatment. They also receive sunscreen products, spectacles for those who require them and some protective clothing to reduce sun exposure. These programs also provide an opportunity for PWA to interact with and support each other through their good and bad experiences.

Summary

Following this introductory chapter, Chapter Two discusses the literature on the experiences of persons with albinism, including myths and challenges encountered in Africa and in Ghana.

In chapter three, the methodology employed in the research is explained. This research draws on the qualitative methods utilised for data collected from each of the twenty-four participants. Thematic analysis was used to analyse the data, where themes and subthemes were developed, as well as the limitations of the study were identified.

Chapter Four discusses the results obtained from the data of the respondents. Themes, subthemes and codes were developed from the transcripts of participants using the six-phase approach employed by Braun and Clark's (2006) in thematic analysis.

Chapter Five discusses the major findings and how they compare with similar studies.

Chapter Six presents the conclusions and recommendations based on findings from the study.

Chapter 2 - Literature Review

2.0 Introduction

This chapter is a review of what is known concerning the experience of persons with albinism in different parts of the world and in Ghana. It provides the foundation to further explore and extend the knowledge on the subject matter. Therefore, this chapter discusses the literature on the lived experience of persons with albinism, their perception of albinism and the support systems available to cope with the challenges in Ghana.

2.1 Scientific description of Albinism

Albinism is a global phenomenon found in almost all populations. In Africa and other regions, the term "albino" is used in reference to a person with reduced or absent skin pigment (melanin) (Federico and Krishnamurthy, 2023)**.** Medically, persons with albinism face a range of dermatological and ophthalmological challenges. The lack of melanin exposes their skin to harmful ultraviolet (UV) radiation, leading to a heightened risk of sunburn, premature aging, and skin cancer (Ma et al., 2023). Visual problems- such as photophobia, nystagmus, and reduced visual acuity- are also common and contribute to significant educational and occupational barriers.

Beyond the biomedical facet of albinism, the mystery surrounding albinism has led to many different interpretations of the phenomenon that are largely influenced by socio-cultural beliefs. In Africa, persons with albinism (PWA) readily stand out due to the dramatic contrast of the lighter skin tone of persons with albinism against the more prevalent darker skin tone of most Africans. In comparison, as suggested by Kromberg et al, in the West, where fair-skinned populations dominate, the condition may be missed or not easily noticed (Kromberg, Flynn and Kerr, 2023) The result of this is a somewhat higher incidence of stigma, discrimination and propensity for violence against PWA in Africa as compared to those living in Europe and North

America and may account for the limited research on the experiences of PWA in the West. The experiences of PWA in Africa in different contexts and the coping strategies adopted will be discussed further.

2.2 Lived Experiences

As with other rare genetic skin conditions, persons with albinism are readily recognised and therefore can be a target for verbal and physical abuse and violent discrimination, especially in Africa (Fournier *et al.*, 2023). These misguided practices, motivated by superstition and ignorance, create a difficult environment for PWA to thrive. Mostly negative experiences affect their social lives and opportunities to gain employment or make a living (*Strength Beyond All Odds… People with Albinism | EEAS*, 2021). The situation is complicated by the peculiar health challenges related to albinism, such as visual impairment and skin disorders, including an increased risk of skin cancer (Brocco, 2016).

2.2.1 Challenges of Persons With Albinism

The impact of stigma and discrimination also has repercussions for the standard of living of PWA. This section describes their challenges and barriers faced by persons with albinism. This includes the social, health, economic and educational challenges that are commonly described in literature from other studies.

Social Challenges

Fournier et al. (2023), in a systematic review of the psychosocial implications of rare genetic skin diseases, examined the psychosocial consequences of these diseases, including albinism, on people's daily experiences. They noted that many adult PWA expressed difficulties in social interactions, sustaining romantic relationships or getting married. They also highlighted the fact that the families of PWA are also impacted. and may receive some form of abuse from community members, which generates stress and fear. Birthing a child with albinism may also become a reason for divorce and family disputes in many places in Africa. It may also be seen as damaging to the social reputation of the family and, therefore, elicit abuse from other family members (Ghana Association of Persons with Albinism, 2019).

It is important to emphasise the role of parental acceptance in the lived experiences of PWA. When parents support and accept PWA, they create a safe environment at home for them to thrive and develop appropriate coping strategies. The converse situation worsens the experiences of PWA and promotes negative outcomes (Brocco, 2016).

Another study in Botswana pointed out that the climate created by the stigma and discrimination fuelled by myths hinders regular social interactions and generates negative emotions and behaviour patterns such as fear, anger and low self-esteem (Anshelevich *et al.*, 2021).

Similar occurrences are found in some communities in Ghana, as described above in other African countries (Doris, 2019). According to Daklo and Obadire (2024), some communities in Ghana do not even allow PWA to reside among them. A narration in this report described an instance where community leaders refused to engage some delegates of PWA to facilitate community entry for sensitisation and education programs.

The social challenges of PWA are a major hurdle that tends to affect their quality of life. Different strategies may be adopted to cope with these and overcome them. Support from family and the activities of various organisations may also prove beneficial in improving their quality of life.

Educational Challenges

Firstly, obtaining quality education may prove difficult. Education represents both a pathway to empowerment and a site of exclusion for persons with albinism. Many children with albinism often do not receive the empowerment needed. On the contrary, children with albinism may be prevented from going to school by parents who intend to protect them from abuse or may drop out of school due to the negative experiences at school (Nebre, 2018). For those who are able to attend school, a notable barrier to education is the problem of visual impairment associated with albinism, which limits the ability to read text from blackboards or screens. This is often not addressed in most schools and impedes learning by children with albinism, leading to poor performance (Tambala-Kaliati, Adomako and Frimpong-Manso, 2021). Unfortunately, in developing countries, teachers have a limited understanding of the needs of PWA, possibly due to a lack of training on the subject. This describes the situation explored by Ndomondo in 2015 concerning the education of children with albinism (Ndomondo, 2015). This lack of quality education may translate into limited employment opportunities later in life and, therefore, a reduced standard of living.

Economic Challenges

Another challenge is the limited means of earning a living due to health concerns. Work which requires long periods in the sun is not suitable for PWAs due to the risk of skin cancer from prolonged exposure (Mouhari-Toure *et al.*, 2021). This suggests that even jobs such as farming, street vending, masonry and other manual labour may constitute a major health risk. In addition to these, there is a misguided perception of the incompetence of persons with albinism. Employers in the formal sector tend to discriminate against PWAs on this account, preventing qualified candidates from being hired (Dapi, Tambe and Monebenimp, 2018). Discriminatory hiring practices further restrict access to stable employment. Many PWA therefore resort to minor self-employment ventures which often yield unstable income (Masanja, Imori and Kaudunde, 2020).

Several studies in Ghana attest to the fact that the economic challenges associated with living with albinism are the same as those described in other African nations. This is possibly due to the similarities in socio-cultural beliefs, superstitions and myths (Kwabena Benyah, 2022; Daklo and Obadire, 2024).

Health Challenges

Oculocutaneous albinism (OCA) is associated with peculiar health challenges. They include impaired visual acuity, hypopigmented skin with limited ultraviolet protection, which predisposes to skin damage and cancers. The various difficulties encountered also affect the psychosocial health of PWA (Ma et al., 2023).

As described earlier, visual impairment affects almost all aspects of life, especially among Africans. The limitation is seen in education, employment opportunities and daily social interactions. In Europe, although access to employment opportunities and education for PWAs is largely unrestricted, discrimination due to visual impairment may be encountered. This may be seen in the inability to meet legislative requirements to obtain a driver's licence, for example (United Nations, 2019).

An important cause of morbidity among PWA is the increased susceptibility to cutaneous damage by solar ultraviolet radiation. This leads to sun sensitivity, sunburns, solar lentigines (small, flat, brown spots), freckling, and, most importantly, skin cancer. Skin cancer usually develops in the third decade of life and can rapidly become too advanced to achieve a cure (Wright, Norval and Hertle, 2015). In addition to this, late presentation, limited access to quality healthcare, and financial difficulties compound the problem and heighten the risk of mortality. Although skin cancer is a concern for all persons with albinism, it has been suggested that those in Africa are at a higher risk due to increased ultraviolet exposure (Wright, Norval and Hertle, 2015; Emadi et al., 2017).

It is prudent to note that actively applying sun protection measures (wide-brim hats, sunscreen, sunglasses and protective clothing) can help reduce ultraviolet exposure and, hence, mitigate the risk for cancer.

Coping strategies

Coping strategies are behavioural and cognitive tactics used to manage crises, conditions, and demands that are evaluated as distressing (Carr and Pudrovska, 2007). It essentially refers to voluntary actions or behaviours developed to minimise the impact of the stressful situation. Coping strategies or styles are, therefore, patterns of behaviour consistently utilised to address these stressors (Algorani and Gupta, 2024). Individuals often develop various strategies to cope with their situation. These may be proactive or reactive. The coping mechanisms employed by PWA have not been adequately explored.

Lazarus and Folkman originally described two forms of coping strategies: problem-focused and emotion-focused coping (Biggs, Brough and Drummond, 2017). Problem-focused coping attempts to find solutions to resolve the problem. Alternatively, emotion-focused coping involves managing the emotions that an individual feels when a stressful event occurs and may include disengagement, avoidance, and emotional suppression. Emotion-focused coping mostly occurs when an appraisal has been made that nothing can be done to modify the harm, threat or challenge. Neither of the two forms of coping is inherently adaptive or maladaptive; thus, individuals may use a combination in stressful situations. The key to successful coping is the use of coping flexibility. It refers to the ability to modify strategies over time and across different stressful conditions, as different strategies work effectively than others depending on the circumstances (Patricia *et al.*, 2015). There are varied factors that can influence the living experience of PWA. The variables, among others, include stigmatisation/discrimination, family and community support, access to specialised health care, economic independence and the coping strategies developed to deal with these circumstances. This suggests that the differing exposures in these sectors can act together or independently to alter their overall experience.

2.3 Albinism interventions in Ghana

Albinism related projects are often carried out in collaboration with the Ghana Association of Persons with Albinism (GAPA). GAPA belongs to the Africa Union of Persons with Albinism (AUPA), of which it is a founding member. The organisation is a major advocate for the interests of PWA in Ghana, including advocating for inclusivity and equal opportunities (Aboagye, 2024). It also organises programs to raise awareness about albinism, to educate its members and empower them to take care of their health needs and to provide support for its members where possible.

Other organisations, such as Engage Now, Africa (ENA), as part of their agenda, support the activities of persons with albinism in Ghana. With the mission to heal, rescue and lift, ENA advocates for persons with albinism, organises sensitisation events to educate the community about albinism and demystify the condition and facilitates eye and skin screening and support for skin cancer treatment for PWA who would otherwise be unable to access these services. They also work to provide livelihood support for persons with albinism by providing financial assistance to students and some members to start businesses (Engage Now Africa, 2023).

The United Nations, on the 18th of December 2014, adopted a resolution to make the 13th of June the International Albinism Awareness Day. This was to help draw attention to the human rights violations and promote the protection of the rights of persons with albinism globally (United Nations, 2015). In Ghana, Engage Now Africa, in collaboration with GAPA, usually takes advantage of this day to organise sensitisation programs and eye and skin screening events for persons with albinism. These programs are organised in various regional capitals in a bid to reach communities in various parts of the country.

2.3.1 Albinism and Disability

In Ghana, persons with albinism were legally recognised as persons with disabilities following the Persons with Disability Act (Act 715) enacted in 2006. The act defines a "person with disability" as "an individual with a physical, mental or sensory impairment, including a visual, hearing or speech functional disability, which gives rise to physical, cultural or social barriers that substantially limit one or more of the major life activities of that individual." (Persons with Disability Act, 2006).

Categorising PWAs as a disability group enables them to obtain support, access to products and services available to other disability groups. It may include scholarship schemes, financial aid and access to healthcare. However, implementation or enforcement of these policies has not been executed effectively or at all. The rights of persons with albinism are still violated, and the discrimination remains. In 2024, the Africa Albinism Network called on the government of Ghana to hasten the implementation of the UN Convention on the Rights of Persons with Disabilities (Africa Albinism Network, 2024). The convention, which was signed in 2007 and ratified in 2012, solidifies Ghana's legal obligations to uphold and protect the rights of persons with disabilities, including the albinism community.

Compared with other disability groups, PWAs face more stigma, discrimination and outright violence. This could be driven by the persistence of myths and superstitious beliefs surrounding albinism (Benyah, 2017). For example, other physically challenged persons may be met with sympathy or compassion in Ghanaian communities; however, PWAs are often shunned and rejected. As some studies have suggested, social stigma hinders PWA from receiving the social support they need (Affram, Teye-Kwadjo and Gyasi-Gyamerah, 2019). Other disability groups, such as people with visual impairment, are not usually victims of ritual killings and therefore less likely to face physical threats to life from their community. On the contrary, people with visual impairment are often given alms in the streets and a target for support from charity organisations.

In addition to this, other disability groups usually have better-resourced institutional presentation compared to albinism groups. Other physically disabled groups are also readily identified as having a disability and accorded some level of support. However, PWAs are not traditionally accepted as being disabled. This may be due to ignorance of albinism on the part of community members. Subsequently leads to the denial of benefits available to other disability groups. The Africa Albinism Network noted this and has called for the implementation of laws and policies asserting the rights of PWA (Africa Albinisim Network, 2024).

Summary

The unique characteristics of persons with albinism make them stand out, especially in African communities. A misunderstanding of this condition due to ignorance leads to stigmatisation and discrimination against persons with albinism. This posture towards them is often the result of superstitious beliefs and ideologies. Apart from the society's perception of albinism, persons with albinism also have unique health risks, such as visual problems and dermatological conditions, including skin cancer, which is fatal when left untreated. The barriers to accessing quality health care heighten these risks and contribute to adverse health outcomes. How they cope with these situations also affects their ultimate experience in the African context. All these circumstances contribute to the overall experience of PWA in Ghana and Africa on the whole. Some agencies in Ghana and Africa have contributed immensely by advocating for the rights of PWA and seeking to provide support to them to improve living conditions, provide opportunities for them to improve their lives and also to meet their health care needs.

Chapter 3– Methodology

3.0 Introduction

This chapter elaborates on the methodology of this study. It presents the research design, the study population, data collection tools utilised and how respondents were recruited. This section provides details on the study design, elaborates on the sampling procedures, how data collection tools were developed and how data was analysed.

3.1 Research Design

The study is part of a larger qualitative study called the Albinism Project. The project is a collaboration between Engage Now Africa (ENA) and Ensign Global College. ENA is an international NGO in five African countries and a sister organisation of Ensign Global College. ENA has three primary programs for PWA: 1) livelihood program, 2) healthcare support and 3) school advocacy.

The Albinism Collaborative Project used a qualitative research design, primarily a phenomenological approach. This design is appropriate because it seeks to explore and understand the lived experiences of persons with albinism in Ghana, with a focus on how they cope with their daily challenges. The phenomenological technique is ideal for research that seeks to get in-depth insights into the personal experiences of individuals and the meanings they attach to them.

This study was explorative as it sought to investigate the perceptions of persons with albinism concerning the condition, how they are viewed in their respective communities and the means of support accessible to them. It also describes the myriad challenges of PWA encountered at various stages of their lives and provides details of these events for analysis.

The project was funded by the Ensign Global College through a board member who is also a board member for Engage Now, Africa. This, however, did not affect the study.

3.2 Data Collection Method

This is a qualitative study which involved the initial development of an interview guide for primary data collection. The interview guide was designed to cover key themes such as myths, perceptions about albinism, discrimination and support systems available to persons with albinism. The data collected also included demographic data such as age, sex, occupation and marital status. Respondents were contacted to schedule suitable times for either a phone call interview or an online meeting using the Google Meet application. The interviews were audio recorded with consent from participants and stored using a cloud storage service (Google Drive). The respondents were initially contacted to inform them about the details of the study, the goals and objectives and obtain informed consent prior to scheduling and conducting the interview. Interview duration ranged from 45 minutes to 70 minutes. This was conducted mainly in the English language, but respondents were permitted to communicate their ideas in their local language whenever they desired.

Out of 24 interviews, 19 were conducted using the Google Meet app and 5 were phone call interviews. This strategy was adopted due to the distance between respondents and the cost required to interview respondents in person. The interviews were conducted with only research team members present. The interviews were conducted by the research team. The team consisted of 5 females and 1 male. Their qualifications include one member with a PhD and multiple publications of qualitative research projects, another with a professional medical degree (MBChB), 3 members who are master's degree graduates who have participated in multiple qualitative research projects and one with an undergraduate degree. All team members have also had multiple qualitative research workshops and trainings over the course of their degree programs.

3.3 Study Population

The target population for this study includes persons with albinism residing in various regions in Ghana, especially those who have participated in intervention activities provided by Engage Now Africa (ENA) and other organisations in selected regions in Ghana. Engage Now Africa is an international NGO in five African countries, Ghana inclusive, and a sister organisation of Ensign Global College. To access PWA's lived experience, about 24 in-depth interviews were conducted, including beneficiaries of the ENA livelihood and healthcare interventions.

3.4 Interview guide

The interview guide (Appendix 1) was developed by the research team. The team developed questions that align with the research objectives. The content of the guide was reviewed by the thesis supervisor and further refined in collaboration with an executive of the Ghana Association of Persons with Albinism (GAPA) to ensure appropriateness. The interview guide was administered during the pretesting phase. Questions that elicited repetitive responses were reframed for clarity.

3.5 Sampling

The sampling method employed is the purposive sampling method. In collaboration with the members of the Ghana Association of Persons with Albinism, a list of various regional representatives was compiled. These representatives were contacted to provide the contacts of members in their respective regions as potential respondents. We collaborated with a GAPA executive who facilitated the process to obtain more contacts when initial attempts to obtain respondents proved difficult with our initial contact lists. Using this frame, out of 36 contacts obtained, twenty-four responded and participated in the study. Others could not be reached with the contact provided. Out of the 24 participants, 5 persons each were from Greater Accra, Northern and Volta regions, 2 persons each from Central and Eastern, 1 from Ashanti, Upper

West, Western, Bono and Oti regions. Some, such as Greater Accra and Northern regions, were oversampled due to non-response from contacts in other regions.

3.6 Pretesting

Interviews were initially conducted among persons with albinism. Two people were interviewed to assess the clarity of the questions and whether they elicit responses that address the research questions. The guide was then revised to eliminate questions eliciting repetitive responses and rephrase questions for clarity.

3.7 Data Handling

Interview recordings and transcribed data are securely stored and accessible only to the researchers. All personally identifying data will be de-identified to protect the identity of individuals who have provided information through their participation in the project. The data obtained was also uploaded onto a password-protected cloud storage database (Google Drive) for ease of access among researchers. Data obtained will be kept for the duration of the study and up to 3 years for future review of the study.

3.8 Data Analysis

Interview audio data was transcribed by research team members. The transcribed documents were de-identified, and a numbering scheme was developed to identify the documents. Coding and analysis were done using the computer-assisted qualitative data analysis software, Atlat.ti. This was also done by all team members. Codes, sub-themes and themes were then generated from the raw transcripts gathered from the participants. In qualitative analysis, themes and sub-themes could be developed from the data either through the research questions or through a theoretical framework (Braun and Clarke, 2023). In this study, the themes were generated from the codes and sub-codes and grouped appropriately to align with the study objectives.

3.9 Ethical Considerations

Ethical approval for the study was sought from the Ensign Global College institutional review board. Informed consent was obtained from all participants, ensuring they were fully aware of the study's purpose, procedures, and their rights, including the right to halt participation at any time without penalty. The confidentiality and anonymity of participants were strictly maintained throughout the study.

3.10 Limitations of Study

Some limitations of this study include the limited sample size obtained, which may not describe the full range of experiences of PWA, although many participants described similar experiences. Another challenge is access to comprehensive reports on the various albinism directed projects in the country by different agencies to understand the projects that were carried out.

3.11 Assumptions

This study was conducted with the assumption that participants provided honest and accurate information concerning their experiences and perceptions of the projects they participated in. it was also assumed that the participants from various regions had similar experiences and perceptions to other PWA that were not interviewed.

Chapter 4 – Results

4.0 Introduction

This chapter describes the results obtained from the study. The data was obtained from respondents from selected regions who shared their perceptions on albinism, the challenges they face and the support systems they utilised. This chapter presents the key findings from the sample obtained.

A total of 24 participants were interviewed. These were made up of 10 females and 14 males. Participants were selected from various regions in the country. Five each from the Greater Accra, Volta and Northern regions, 2 each from Central and Eastern regions, 1 each from Ashanti, Oti, Western, Upper West and Bono regions. Participants were assigned codenames and identified as D1, D2, D3…D24.

4.1 Demographics

Table 4.1. Showing the sociodemographic characteristics of participants

	Age (years)	Sex	Marital Status	Level of Education	Occupation
D1	23	Female	Single	Tertiary	NSS personnel
D2	28	Female	Married	Tertiary	Trader (Self-employed)
D3	27	Female	Single	Tertiary	Student
D4	22	Female	Married	Secondary	Unemployed
D5	31	Female	Single	Tertiary	Student
D6	31	Female	Married	Tertiary	Nurse
D7	44	Female	Single	Tertiary	Teacher
D8	27	Female	Single	Tertiary	Student
D9	24	Female	Single	Secondary	Unemployed (Just completed SHS)
D10	33	Female	Married	Tertiary	Assistant Admin. GAPA
D11	50	Male	Married	Tertiary	Self employed (Owns a school)
D12	28	Male	Single	Primary	Unemployed

D13	32	Male	Married	Primary	Self employed (Phone repairer)
D14	36	Male	Married	Tertiary	Student
D15	31	Male	Single	Secondary	Motor rider (Self-employed)
D16	24	Male	Single	Tertiary	Teacher
D17	38	Male	Married	Tertiary	Farmer (Self-employed)
D18	39	Male	Married	Secondary	Electrician (Self-employed)
D19	26	Male	Married	Secondary	Electrician (Self-employed)
D20	41	Male	Married	Tertiary	Educationist-GHS
D21	28	Male	Single	Tertiary	Programs & research officer
D22	28	Male	Single	Tertiary	Student
D23	36	Male	Married	Secondary	
D24	25	Male	Single	Tertiary	Student

About 70% of participants were within the age range of 20 to 35 years. Despite educational challenges, about 67 per cent had completed or were pursuing tertiary education. Among all the participants, only 4 were unemployed. Others were students or gainfully employed.

Table 4.2. Showing frequency distribution of sociodemographic characteristics

Variable	Frequency (n=24)	Percentage (%)
Age		
20-25	5	20.8
26-30	7	29.2
31-35	5	20.8
36-40	4	16.7
41-45	2	8.3
46-50	1	4.2
Marital status		

Married	12	50.0
Single	12	50.0
Level of education		
Primary	2	8.3
Secondary	6	25.0
Tertiary	16	66.7
Occupation		
Employed	20	83.3
Unemployed	4	16.7

4.2 Summary of Themes

The table below summarises the main themes and sub-themes identified in the data collected. The main themes identified are community perceptions of albinism, PWA perceptions of albinism, challenges of PWA and support for PWA. Community perceptions of albinism were mostly negative and demeaning, while persons with albinism viewed albinism more positively. Challenges faced arise from various facets of life, such as healthcare and human rights violations. The support described by participants came in the form of support from NGOs and government agencies, which was termed formal support. Persons with albinism also received support from family, friends and colleagues in various ways, and this was termed informal support.

Table 4.3. Showing the main themes and sub-themes

Themes	**Sub-themes**
Community Perception of Albinism	1. Spiritual Myths 2. Dehumanising Myths 3. Myths about Qualities of PWA 4. Health-Related Myths 5. Diet-Related Myths
PWA Perception of Albinism	1. Humane Descriptions of Albinism 2. Health Characteristics 3. Positive spiritual attestation
Challenges of PWA	1. Discriminatory Practices 2. Health challenges 3. Economic challenges 4. Educational challenges 5. Social challenges 6. Human Rights challenges 7. Environmental challenges
Support for PWA	1. Formal Support 2. Informal Support

4.3 Community Perceptions of Albinism

Many communities in Ghana have different beliefs concerning the phenomenon of albinism. Participants elaborated on various superstitious beliefs of their respective communities. These were categorised as spiritual myths, dehumanising myths, diet-related myths, myths about their qualities and health myths.

4.3.1 Spiritual Myths

Respondents described spiritual myths where persons with albinism were described as spirits, ghosts, witches, cursed or descended from gods. Other reported beliefs that PWA have light at their fingertips. A participant mentioned that some people in the community would refuse to sleep in the same room with a PWA due to the fear of spiritual encounters during the night.

"Okay, people normally believe that if you are living with somebody with albinism, they are witches, and they are bad luck in the society." D8

"if a person with albinism slept in a room with those with non-albinism, in the night you would turn and be riding them in a spiritual realm." D2

Another commonly held belief reported by persons from different communities is that persons with albinism are from water bodies, such as streams, rivers or born to river gods. Terms such as "nsuoba"(translated-child of water or water-child) were used to describe them.

"The common ones are, I quite remember growing up, there was this superstition that there was one stream at my place. This stream has some spirit. So there was this stream especially, when they see me, they would call me by that name. I am the son of that stream." D16

"They, said er we albinisms we are er… let me just make they say we are "Nsuoba" so we are gods, let me just make it that way… so we have bad spirit in our, in us so you near the person, you, he make friend with you is going to affect his business or his life." D23

In all, about 17 of the respondents described some form of supernatural or spiritual myth they had heard from their community members concerning persons with albinism. These myths ostensibly influence the attitudes and behaviours exhibited by the community towards persons with albinism.

4.3.2 Dehumanising Myths

Participants also reported misconceptions about persons with albinism that dehumanise them and suggest that they have traits that are unnatural to human beings. These perceptions deprive PWAs of features or attributes that are commonly ascribed to humans in general. For example, PWA were described as not having blood or being non-human. Some were described as incomplete as humans, while others reported that they cannot die. These myths within the communities portrayed persons with albinism as being unlike other human beings.

"In my childhood age, they saw me like a robot. Yes, they don't believe that I am a human being. They don't believe I have blood. Yes, they don't believe that." D12

"And so, yes, people of this color has fallen from him. By implication, it means that they were, or we are not fully formed, you know.... So the name is, they mentioned the name "Gele Sosi", which means that not fully formed before the person fell from the deity's soul." D14

About 16 respondents from different communities noted the myth that persons with albinism cannot die. This suggests a widespread belief that is held by many communities in Ghana.

"You see that, you will be with your friends and another person will go like, oh, you people you don't die ooo, they don't see." D16

"A lot of people were saying to, we don't die, we vanish..." D19

Another characteristic ascribed to PWA is that they don't defecate on Fridays. Participants reported that this was often said in jest to tease or mock them. This was mentioned by 12 respondents.

"There are very popular ones. The fact that we don't die and we don't ease ourselves on Fridays. I say that." D10

"Yeah, those ones. Yes, including the ones that I said about when I was in was in secondary school, the Friday, they don't defecate, we don't defecate, that kind of thing, that myth..." D14

Although most of these beliefs could easily be debunked, community members still held on to them and were often used as insults or to make derogatory remarks about persons with albinism.

4.3.3 Myths about qualities of PWA

Participants described myths about the qualities or abilities of persons with albinism that were held by their respective communities. They include assertions that PWA have limited strength compared to others or are "useless" people in the community. This myth erroneously minimises the capabilities of persons with albinism and was often used to ridicule them.

"So as for that, they complain a lot about us that we don't have the strength like them." D12

"And they should also remove the mindset of people having it as if maybe it's a curse or like they are uselessly useless. Their existence is uselessly… or they are not valuable to the progress of the community and the country at large." D15

Another belief recorded from different communities was that persons with albinism have "bad luck". The idea was that encountering PWA in the mornings would lead to an unproductive day at their workplace or businesses. They also iterated that having a relationship with a person with albinism would lead to terrible outcomes, such as poverty or even death. About 6 respondents reported instances where they were berated with these comments.

"Like if they'll be telling you that if they see you in the morning, they won't get money or they will not get this and this. That is what they will be telling you." D1

"Even if a person with albinism marries to a well-to-do man, the person will automatically become poor… people were saying that if he married me, he wouldn't even live up to one month. He wouldn't do this and other things. D2

"Another one is that persons with albinism are a symbol of bad luck, that is to say, when they are with you or close to any person, it will be hard for the person to progress in life." D24

4.3.4 Health-related Myths

Another group of myths are the health-related myths espoused by community members. These are myths about the health and basic physiology of persons with albinism. They include comments that PWAs don't have blood or are completely blind, especially at night. Others suggested that albinism can be transferred from one person to another by contact.

"And they say if you go near a person with albinism, you also give birth to a person with albinism." D4

"Some are saying when they touch us, they become like us. So many things." D19

"But the people that I'm living with, they just refer to us as if we can't see. We are totally blind. And those things, it makes us feel so lonely." D15

The consequences of the belief that albinism is transferable is that community members may shun their company and avoid making friends with persons with albinism. Subsequently, this can be the driving force behind some of the social challenges experienced by persons with albinism.

4.3.5 Diet-related Myths

A less common myth among respondents was the diet-related myths. One respondent noted that they had been told they were not supposed to eat too much salt or eat catfish. Although they were unable to ascertain what the supposed consequences of these actions were.

"Well, when I was growing up, I hear that they used to say that we shouldn't take too much salt. And then they were saying that we couldn't eat catfish. I don't know if that's catfish." D10

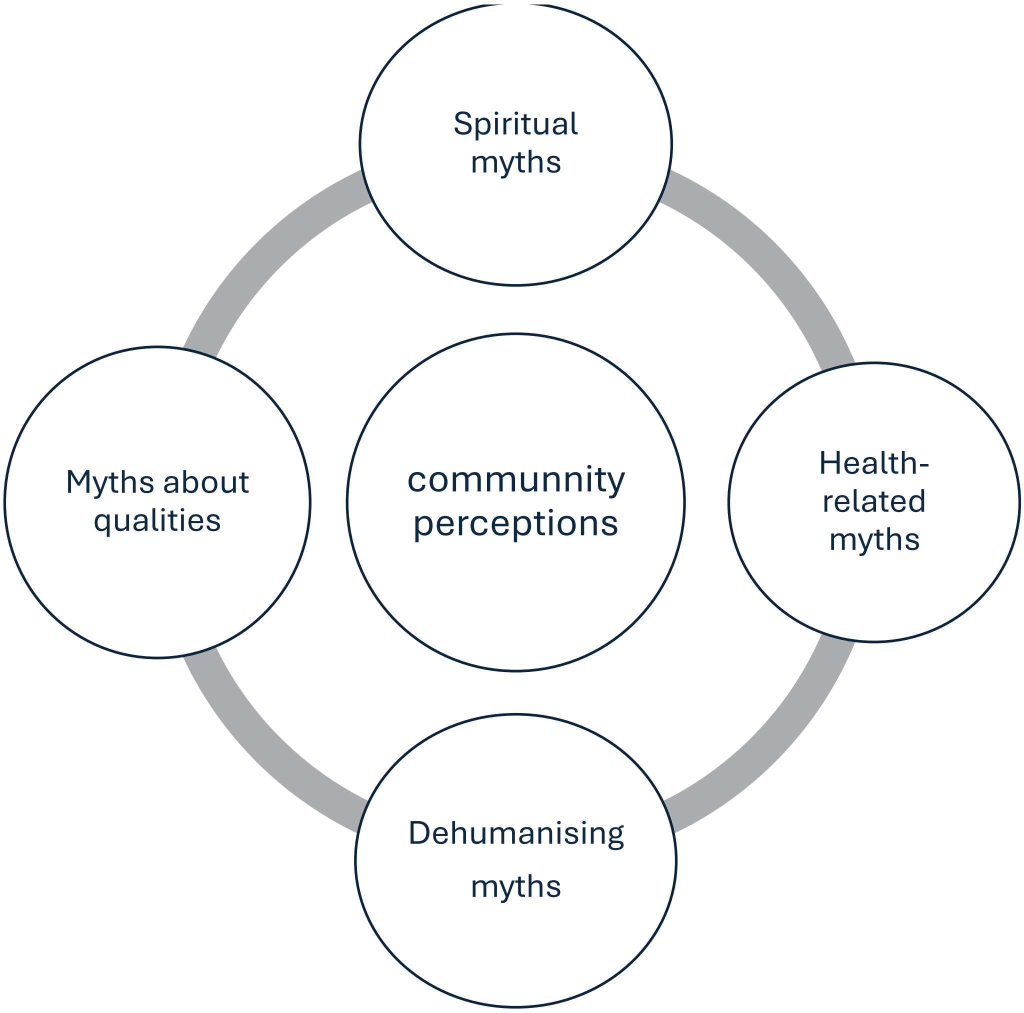

Figure 4.1 Diagram showing community perceptions of albinism

4.4 PWA’s Perceptions of Albinism

Persons with albinism often describe the condition with positive and humane terms. Although they acknowledged the condition made them different from others, they accepted that it did not make them any less human, but rather unique with both good and bad characteristics. The responses were grouped into humane descriptions, health-associated features, and positive spiritual attestations.

4.4.1 Humane Descriptions

Many respondents described albinism as a naturally occurring or genetic condition rather than a disease. It makes them unique or different in some way from others who do not have the condition. In contrast to the myths described, they also characterised themselves as human beings. About 20 respondents used these terms to describe albinism.

“It's a natural thing. It's just the absence of that element, the melanin. Yes.” D14

“Okay, so I was saying albinism is a natural condition. And then it has a lot of genetics, lack of melanin in the body. And so, it's normal for everyone to have… it's a unique nature. Albinism is natural.” D21

“I think... people have a lot of concepts about person with albinism, but I think this is totally changed. This is totally changed genetic. That is what I would say. It's not a disease though, it's just a condition.” D6

The respondents had accurate knowledge of the condition albinism and also utilised humane terms to describe albinism. This suggests a positive view of albinism as opposed to the negative ones espoused by the myths.

4.4.2 Health characteristics of Albinism

Respondents were also aware of the features of albinism and some associated health conditions. They include lighter or pale hair and skin colour, which some noted was from low or absent melanin in hair and skin (n=8).

“So we have a colour difference. Some with their hair and some their body colour.” D21

“In my own words, albinism is a condition. So, as we all know, there's a lack of the pigment that creates the black skin In our system. So once we lack that, that ends up giving us this color. And then that is, in my own words, that is what I would say.” D7

Some health-related conditions are the eye problems experienced by many persons with albinism in varying severity. About seven participants highlighted this problem. A few participants also described albinism as predisposing to having a disability due to the health challenges faced by some persons with albinism.

"Actually, the truth be told, when the sun is shining, we don't see that much. But the people that I'm living with, they just refer to us as if we can't see. We are totally blind." D15

"Naturally, persons with albinism have sight issues, so the ability to see far is quite a difficulty because of the lack of pigmentation in their eyes. We are sensitive to light and we are not able to see far. This also varies from a person with albinism to another person with albinism. The extent to which I can see varies from the extent to which another person with albinism can see. But most people have come to the conclusion that persons with, every person with albinism is blind, which is not the case." D22

"Okay. Please the people must be educated on how… on the type of people we are and that we are all equal. Not a curse, or a disease. It's a disability." D9

4.4.3 Positive spiritual attestations/attributes

Several of the myths mentioned in the communities were spiritual and often had negative connotations. About four respondents also attached spiritual attributes to albinism, which are more positive and optimistic in contrast to the myths. They described it using terms such as a blessing, a gift from God or a wonder of God.

"Well, I would say albinism is a blessing. But the society made it look the other way around, that we are cursed. Because I can see the potentials in us. Even some of the blacks, they don't understand how we usually do our things. So I would say albinism is a blessing is a blessing to the society." D13

"*Ooh, if I say Albinism…Albinism…I don't know say it is inability that way because Albinism is a, is a gift for me."* D23

4.5 Challenges and Barriers Encountered by Persons with Albinism

4.5.1 Discriminatory Practices

As noted earlier, persons with albinism are subjected to discrimination in various ways. All the respondents described instances where they experienced discrimination in one form or another. These have been categorised as mocking, social rejection and perceived lack of competence.

Teasing or Mocking

Several respondents reported being teased, mocked, called unpleasant names and being a target for derogatory remarks. Some comments reported are that they are not human or that they are useless. They are also called names in the local languages, such as “ofiri” or “ofiri djato”

“ *So anytime you go close to them, they give you all sorts of names, mocking you and a whole lot. So it feels to me like, you feel like you are not part of them. So sometimes in terms of taking part in certain communal activities, like maybe taking a position, it becomes a very big challenge.*” D5

“*I will say yes but is just like something like mockery. Sometimes if you’re passing by then you will hear some people shouting ‘albino’ or ‘ofri’ or something like and then embarrassing you*.” D11

Social Rejection

Another form of discrimination endured by PWAs is the rejection by community members, peers and family members. Fifteen respondents described circumstances where they felt rejected, which occurred in different phases of their lives. This can promote social isolation and its attendant consequences, such as mental health effects.

"… if you come out in the house alone and your mom is not around they'll be beating you like pushing you away like you shouldn't come closer to them because your mom is not around that is only your mom who can give birth they don't want to give birth to your type that you cannot do anything. What you should do is that you can only eat and sleep. That is the only thing that you can do. So you shouldn't even come closer to them. Even if you go closer to their children, they will come and push you away, that you shouldn't go closer to their children." D1

"So, when I get to the school there, unfortunately, I couldn't even get a room to sleep. None of them accept me. They said I will sleep with them. That if I sleep in their room, they can't sleep and other things… I was in day school for about one and a half year. So, when I was in the day school and in class, nobody wanted to associate themselves with me." D2

The rejection came in various forms. Some reported their potential marital in-laws disapproved of their relationships, which led to the end of their relationships. Others mentioned that they were unable to participate in community activities or take leadership roles because their communities did not accept them

"And when it came to marriage, I dated someone, the person loves me. I also love the person. But when it came to marriage, the family ignored me. They said they would not allow the person to marry me because of my skin colour." D4

"I remember a brother of mine vied for the position Assemblyman. It was also as a result of this condition and then they rejected him." D5

One respondent reported that sometimes traders at the market refuse money from them, so they are unable to purchase items.

“Yes. Because you go into the marketplace to buy something and they reject your money. But it's also a part of discrimination.” - D8

Persons with albinism also face rejection in potential romantic relationships and marriages. About seven respondents admitted to the difficulty in finding potential suitors and maintaining these relationships when they do find them.

“*Yeah. I was going out with a guy, but due to what the mother and the other family members said, they told him, and the guy decided to walk out of that”* D7

“And also, the marrying aspect too is also a problem. Maybe someone comes to you and the person discusses it with a friend or family member they will say you are an ordinary person you can’t marry this kind of person, they are not meant for you then the person will leave, so it’s affecting me a whole lot.” D8

Persons with albinism experience significant stigmatisation, which also fuels the discrimination they encounter. Eight participants drew attention to this and noted how it related to the prejudice. The stigmatisation is also promoted by the myths and misguided beliefs associated with albinism in Ghana.

“That's it. They tell all of you that there is no space. But before you realize, they have already picked the two and they've left you out. ... when I call, I did a follow-up ... he was telling the boss. The ‘ofri’ guy is calling, what should I tell him? But I could hear from the call on the phone. So, you can have the same qualification with everyone, but because of your nature as a person with albinism, you are being disqualified.” D21

Overall, rejection in its various forms is a major form of discrimination experienced by persons with albinism in different stages of their lives. This can have lifelong consequences to their health, education, employment opportunities and livelihoods.

Perceived lack of competence

Due to the myths circulated in the communities, persons with albinism are perceived to have questionable abilities compared to others without the condition. This assumption is used to marginalise them and prevent them from participating in community activities and even basic house chores. This discriminatory practice, in some cases, came from family members. It also serves as a barrier to employment. Some participants suggested that employers with this perception refused to consider them for employment and, therefore, limited their career opportunities.

"…my father's family, they gave us some names, a whole lot of names. And in general, they were describing us as non-important people. For us, we can't contribute anything effective to the family. And then, you know, in the community, even your house has discrimination, so how much more the community?" D5

"It hurts me a lot, per my field, if I'm going to do electrical work, they will look at me and say someone who lacks vision can he do this work. For my area here that's what I can say." D18

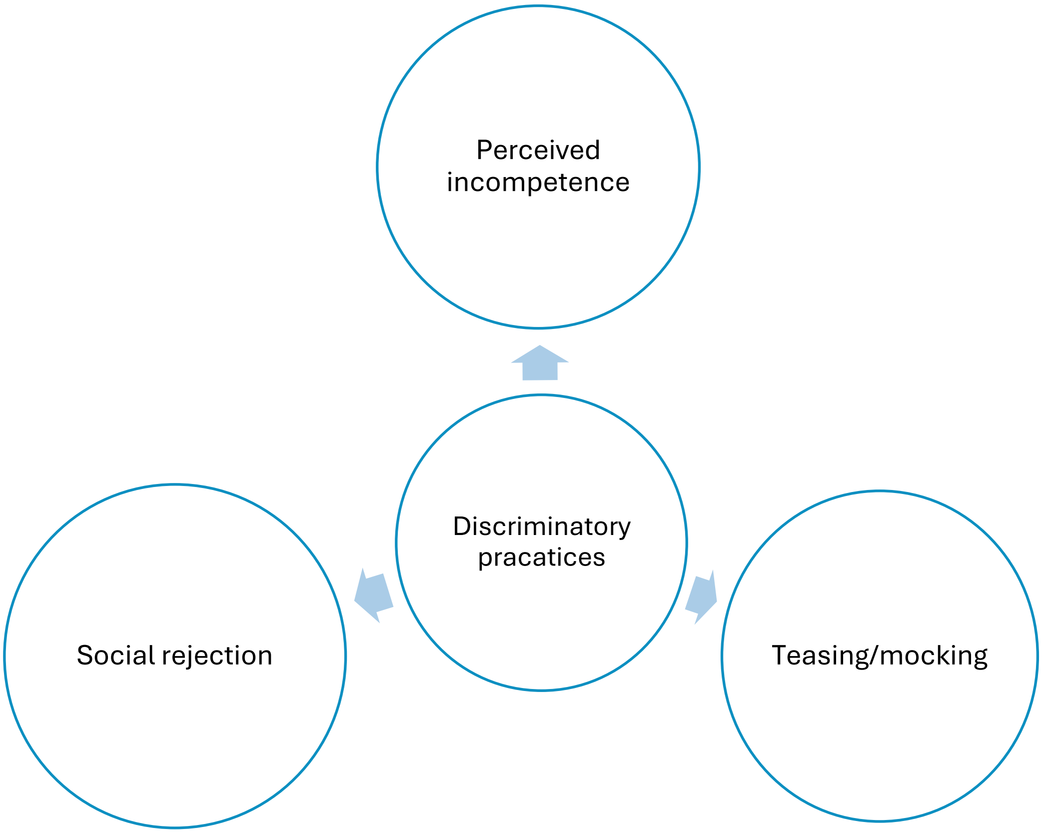

Fig 4.2 Diagram showing discriminatory practices against PWA

4.5.2 Challenges of Persons with Albinism

Health Challenges

One of the major challenges encountered by persons with albinism is the health-related issues associated with the condition. The respondents shared their knowledge and experience of health challenges. The main issues of concern were the skin disorders and associated skin cancer risk, varying degrees of visual impairment, and a health system that fails to address their challenges adequately.

"The experience that I have for skin cancer is that the problem about my skin is when I go outside, when the sun was shining, Yes, when the sun touches my skin or when the sun shines

on my skin, the color of the skin will change immediately when I go out in the sunshine. The skin will change immediately and if you touch it, I will feel pain." D12

"Yes…I was saying that, like, the… because of the sun, excessive sun scorch, the rays, the too much sun rays, my body becomes red then sometimes it itches me then it got swollen and become sore." D9

One participant had already had surgery to remove a skin tumour.

"I go and then there is a tumor suspected to be a cancer and as I'm talking to you now, a surgery has been done and then it has been removed. Yeah. And I'm okay. For now, I'm okay. This is what I have experienced so far." D17

Visual impairment poses a significant threat to the affects their education, employment and overall quality of life. Several respondents struggled with this problem. Sixteen respondents reported this as a major concern.

"My eye is a problem for me for now because it is sometimes it is hard for me to see things afar" D3

"Then the sight, my sight, I would like to do a lot about reading, writing, I cannot cook erm and many others, they are the challenge." D11

Another problem compounding their health challenges health system that fails to attend to their needs. The respondents shared experiences of limitations in access to adequate health care.

"We're not getting the necessary skin care or eye care for our, our body is, is our, is also our challenge." D1

"When it comes to health, I would say for health, I've not been treated with any serious health issue, but I've been denied access. The one which is most at times at the township ...in Ghana here we need to be assisted, sometimes they will be telling you sorry go and come, here and there. That's the situation that we are facing." D16

Others noted the ignorance of health care workers about albinism and associated health issues. This means they were unable to obtain the needed assistance from health care workers.

"So, in the health sector, there are doctors and nurses who still don't understand albinism. They don't have much knowledge or some don't even have knowledge at all about albinism. So, there are times you visit the hospital and then how they interact with you is kind of unfriendly. It makes you uncomfortable. In fact, you don't even want to share why you are in a hospital meanwhile you went there for treatment. But due to those unfriendly interactions and they kind of don't act as professionals which is kind of worrying". D22

Some mentioned blatant discrimination by health care workers whenever they visited the hospital for one reason or another.

"Going to the hospital, you look different, they don't want to even attend to you. Even when they attend to you, they treat you rudely. The way they speak to you, the way they treat you is not nice. Living in this community is not just... I don't know how to even put it." D8

"I was in labor right and when you are in labor when you have a concern you raise it it's like there was some sort of neglect I remember I felt like pushing in the moment that she didn't really she didn't want to attend to me but she had to there was no it's like nobody was available so she had to so you could see there were reservations about it and then I remember I told her that I felt like pushing and she was like oh no it's nothing I'm just being dramatic also there was another midwife who was attending to another person closer she was the one who I was

like, oh yes, the baby's head is actually showing who it was doing. I remember that she was quite harsh in her words." D10

Economic Challenges

Persons with albinism often endure unique economic challenges in Ghana. These challenges are generated by the myths, stigma and discrimination to which they are subjected in the community. The challenges present in different forms. Twenty participants were able to elaborate on the ways the condition of albinism has influenced their livelihood and economic deficits. The challenges appear in the form of limited sources of income or employment opportunities, unemployment, perceived limited productivity, and limitations of career advancement.

Due to health challenges such as sensitivity to the sun and disabilities such a visual impairment, there are some limitations to the jobs persons with albinism can perform. Jobs which require extended periods outdoors, such as farming, are unsuitable for persons with albinism due to increased risk for skin disorders, including cancer.

"..., economically, you see, let me say, as my colleagues can do maybe side jobs, I cannot do that because the sun is not favourable for me. The sun is not favourable for me. So whatever, maybe you can be under the scorching sun and do, I cannot, or let me say, mostly health issues. I have to consider that. ... You wish you can do better, but your condition also limits you in some way." D6

"I want to see changes, because for me now, I'm not working, but if I I work and I am also to protect my skin. For a person with albinism you cannot do a work like selling in the streets. The work we can do best is like sitting in stores or offices. That is the best work for a person with albinism. Our skin doesn't like sun." D4

Some participants also complained of unemployment, which they would suggest is related to discrimination in the recruitment process of companies and institutions they applied to work for.

"when it comes to the economic problem finding work is a bit difficult, if it's not in the public sector and its the private sectors it is a very bit difficult because the person will be thinking about you and how the customers will react and other stuff so finding job in your locality is sometimes a little bit difficult." D3

They relayed that although they met the requirements to be employed, they were often dismissed shortly after they appeared for interviews or disqualified due to their condition.

"I lost my father, and then my mother was jobless. So I wrote many applications, but none of them went through. Sometimes when I send the application, they may call me all right, but immediately I get there, and then they see my personality (appearance), then he rejects. So I tried and tried and tried, but because of my personality, I couldn't get a job." D5

"It is affecting me a lot. Actually, when I applied for jobs, I remember going for an interview and the panel, they asked that, with this condition, do you think you can do our work because most of our work is paperwork, and we believe that you people cannot see because of that I couldn't get the job that I wanted from them." D8

Others mentioned that the myths surrounding the competence or abilities of persons with albinism are also present in the workplace. This means that even in the workplace, they are unjustly considered unfit for certain duties or unproductive for no clear reason other than their skin pigmentation. In some instances, the discrimination from potential customers in their line of work means that they are unable to realise significant gains as compared to colleagues with pigmented skin.

"*So economically, I also worked as an insurance agent, and basically, we had to go to the field to look for clients. Due to my colour, most people didn't want to buy the policies from me, because most of them were uneducated. ...So once someone was assigned to buy policies from you, they were kind of hesitant. So, my colleagues got a lot of clients, more than me. So, at some point I had to quit, because it was not helping me."* D22

"Later, they were confessing to somebody that when I came, they thought I wouldn't be able to handle the children, that kind of thing. So they were, in a way, undermining my ability to work." D14

Another financial challenge arises from the limitation of career advancement. This can sometimes be due to a disability such as visual impairment. It could also be limited funds to pursue further education to upgrade their knowledge and skills.

" I would like to maybe go into other economic activities like farming maybe driving and all those things but I am limited to do it. Anything that has to do with sight, I can't do much about that." D11

Ultimately, these challenges tend to limit the sources of income of persons with albinism in Ghana. This impacts their ability to access healthcare, purchase sunscreen or protective clothing and eyeglasses, for example, and can significantly affect the quality of life of persons with albinism.

Educational Challenges

Persons with albinism face challenges in formal education, in particular. Eleven respondents drew attention to these particular challenges, and some others also hinted at them. These challenges mainly arise from the impact of limited vision and the neglect of the unique needs of these students. Poor education can subsequently lead to poor grades and limitations on future employment opportunities.

Impact of Limited Vision

The prevalence of varying degrees of visual impairment is one of the challenges that significantly impact the education of PWAs. Several respondents reported that their visual impairment impacted them from primary to tertiary education level. It often leads to school some dropping out of school especially when combined with the other discriminatory practices and stigmatisation they are subjected to in the schools. The impairment can therefore lead to poor academic performance in students who would have otherwise performed better if the needed support was given.

"*Our challenges is the education. So the education, because of the eyes errh the sight, some of us are not being able to finish our education or being part of the school, this thing. So we are facing challenges about the education. And again, our health."* D1

Systemic educational neglect

The inability of school authorities to recognise the needs of students with albinism and possibly make adjustments constitutes a neglect of these students. These students are left to deal with this problem on their own, either by trying to get closer or copying notes from other colleagues.

"When I was in school, as a person with albinism, we find it difficult to see because of our sight is not good enough. So when you go to class, the teacher will come and you start teaching, because you cannot see. You find it difficult to understand what the teacher is saying or even for a teacher to teach, he has to write it on the board, As for me, I find it difficult to see, so I have to sit beside my friends." D4

Environmental Challenges

The climate where persons with albinism reside also poses a challenge to their health. Areas with more sunshine would mean higher exposure to ultraviolet rays. This increases the risk of skin disorders, including skin cancer. Nine respondents highlighted this problem.

"I think for Ho the weather is, yes, the weather is better than some other parts, especially in the north, where the sun is in some way almost always too much. But over here, you know, we have the trees and the weather in general. It helps. Apart from that, yeah, that's it. That's it." D14

"Okay the, because of the, because of the weather of, the weather…of the…of, of Africa or the area in which we found ourselves. Now the weather is hot and we cannot be…somebody cannot be selling pure water while being an albino. To be, he or she will be affected." D9

Human Rights Challenges

In some circumstances, the myths and stigma lead to different forms of abuse and violation of human rights. These include verbal, emotional, physical and even sexual abuse as hinted at by one female participant. The physical abuse reported by some is quite serious. It includes extreme violence, threats to life and even murder. In some communities, the superstitious beliefs surrounding albinism drive this violence to obtain body parts for rituals.

"There was this one of my lecturers too was following me like that. His intention was that he needed my hair for a ritual." D8

"… because of the skin they think like you cannot do anything or something like that. And some of them, they rape us." D1

One respondent reported an incident where a group of persons with albinism visited a community for the purpose of awareness creation and education. However, they were vehemently opposed, and their lives were threatened. The threats were not carried out largely due to the presence of the police escort they went with.

"Again, we were prevented, we were nearly attacked if not because, if not we had the help of the Ghana Police Service that we sent there, we might have been attacked and killed. This is one of the harrowed experiences that I had as person with albinism" D20

Social Challenges

This takes the form of difficulty in making friends, establishing and maintaining meaningful relationships. Sometimes, supposed friends were the source of hurtful taunts and teasing. Some respondents drew attention to this challenge, especially during their time at primary and secondary schools.

"Sometimes even the teachers themselves will be shouting at you to sit down or making or passing out some comments, throwing marker or chalks at you to sit down and all other kinds of stuff. Sometimes school, we cannot go out to socialize because when people see you coming out, they just run." D21

Others experienced embarrassing moments with colleagues and also feel embarrassed because they are constantly taunted and teased in the community. A few also reported the lack of emotional and social support from their families. This worsens the feelings of isolation and social rejection they experience.

"Sometimes if you're passing by then you will hear some people shouting albino or ofri or something like and then embarrassing you. "As he is going he can't see oo, look at the eye, ei

look at the face, they can't see ei, there's a stone ahead of you, ei you will fall down oo". So they'll be something like mockery, so when they do that, you become embarrassed, and you'll just go ahead." D11

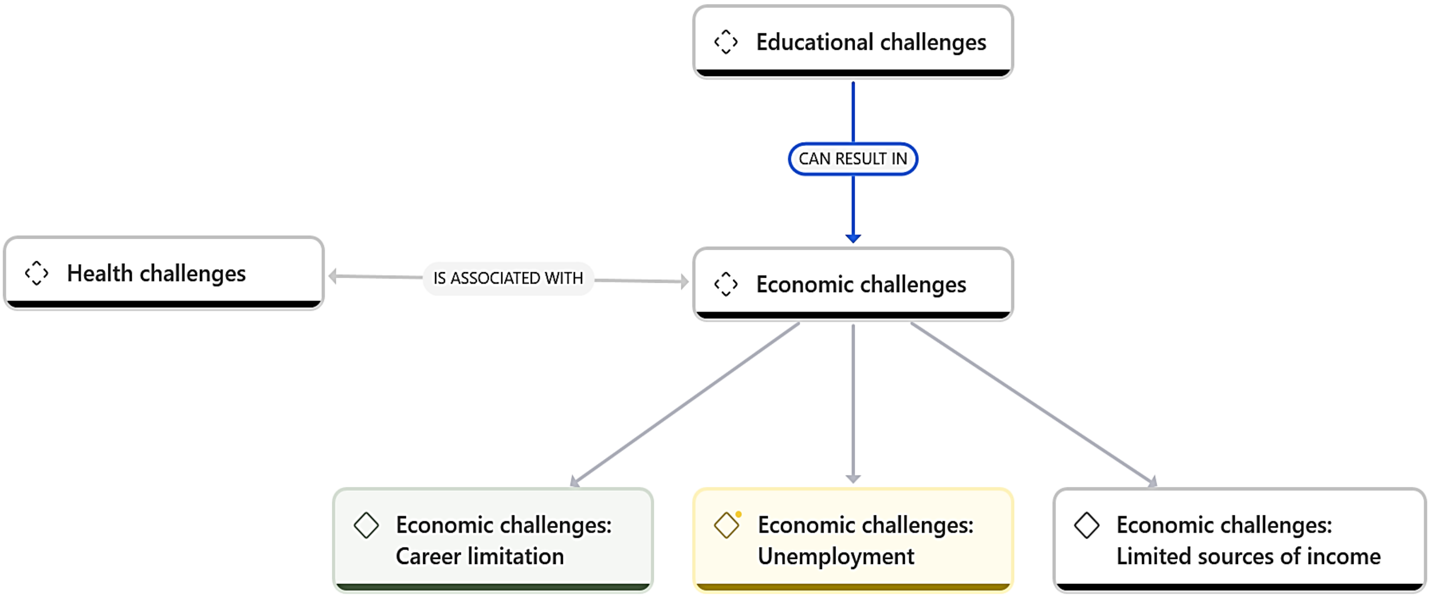

Figure 4.3 Diagram showing the interconnectivity of challenges of PWAs

4.6 Support for Persons with Albinism

In the midst of the challenges, persons with albinism are often left without much support. However, some organisations have championed their cause to provide some assistance for persons with albinism in Ghana. Some respondents have had encounters with some of these Non-Governmental Organisations, such as Engage Now, Africa, that have made efforts to provide some assistance to them. Others also obtain support from their families and friends to attend to their needs. A few also reported that they have not been able to access some of these support systems, and their families have also not been very helpful.

4.6.1 Formal support

Organisations such as Engage Now, Africa support persons with albinism through community education and awareness campaigns, provision of sun protection clothing and sunscreen products, as well as organising eye and skin screening events for persons with albinism.

"I didn't know how to take care of the skin, how the sun affects the skin, and how the sunscreen can help the skin. That was where I learned all those things. So that was where I got to know that the sun can cause cancer to the skin, sun can damage the skin. There is a .... called sunscreen which can help the skin protect it from the sun." D1

Others were able to obtain financial support to help with their education, obtain employment opportunities, or support businesses or to receive health care.

"Engage Now Africa, they financially support me complete my course…And they also support me to do my intensive. When I completed, they also supported me to do an intensive program." D2

One woman is a trader. So they gave her some money to invest into a trade. And the brother too was supported. He's a farmer. And then I knew one lady too at a Adukrom, again, And then one small girl too, I know, on the way to Koforidua, they sponsored her to enter into, start schooling, let me put it that way. Yeah. And then I know of some siblings too that's Engage Now Africa, help them to, to further their education. So yeah, yeah, I know. And then even, let me comment with this one. We had a visitor from, is it Czech Republic or so? They were, they came and then trained us in the suncream production. I remember. That's my area there. D7

Other organisations that have provided assistance to the albinism community are the Ghana Federation of Disability organisations, Africa Albinism Network, Ghana Association of Persons with Albinism, Voice Ghana, and some local government institutions.

4.6.2 Informal support

Apart from NGOs, persons with albinism also receive financial and emotional support from family and friends. Acceptance by the immediate family has helped some maintain good mental health despite discrimination and stigmatisation from community members. It has helped some develop good coping mechanisms in the face of all the challenges.

"For my family, treat us like everybody else. We don't really see the color because I my siblings and I, we are three, we are all people with albinism. So, for the family, the normal thing…For the community, some people are okay with us. We have friends. I have friends in the community. I have people that I am cordial with. And then there are some people that we've been getting because they don't know how to relate to you. Let me put it that way. Because when they see you, they see you as a foreign entity or a foreign being." D10

"But my parents, they understand that I am from God. I am a blessed child for them. So, my parents, they don't joke with me. They take care of me every day. They do things for me to feel okay. ....Apart from my parents, I don't have any other friends outside. The only friends I have is my father and my mother, my sisters and my brothers. My family relatives, that's all. Apart from them, I don't have any friends among them." D12

For some whose parents had accepted them, they continued to be a source of motivation and encouragement to PWAs to help them with some of their challenges.

"So, if I go and tell my mother what I'm facing in school, she would tell me that I should keep on going, I shouldn't give up. So that was what she was telling me...And my mother was like, she kept on telling me that I should never give up, that I shouldn't mind them. I shouldn't mind them". D1

Respondents also noted the support they receive from friends. This also comes in the form of financial and emotional support.

"And then I have colleagues, my friends, my course mates whenever I call, they send their support. And then at times, I have friends who have been supporting me emotionally, socially, and financially. Especially some of my elders, like persons I've been living with." D16

Among persons with albinism, they have been able to organise through the establishment of the Ghana Association of Persons with Albinism (GAPA). This has enabled them to forge support networks and mentorship programs. It also serves to advocate for the albinism community and garner support for them.

"GAPA Is our association. Our association that we joined. I got to know through my teacher. He gave me the number of one of our leaders, and then he introduced me to the group. And they started motivating us, giving advice, teaching us how to care for our skin, and those kind," D4

Chapter 5 – Discussion

5.1 Introduction

This chapter presents and summarises the key findings of the study to investigate the lived experiences of persons with albinism in Ghana. It elaborates on them and discusses the relevance of these findings and how the themes identified are related to each other.

5.1 Summary of Findings

The study sought to explore the lived experiences of persons with albinism in Ghana. It investigated the perceptions, myths and beliefs associated with albinism, described the challenges faced by PWA and the support systems utilised by them to cope with these challenges. This research adds to the body of knowledge on the lives of persons with albinism in Ghana and identifies the support and the relevance of this support. The findings were categorised into perceptions of albinism, challenges and barriers and support for persons with albinism. These three major these have subthemes that will subsequently be discussed.

Participants reported how albinism is perceived in their communities. Many elaborated on various myths and beliefs held by the community. Myths were grouped into dehumanising myths, health-related, spiritual, diet-related and myths about the qualities of persons with albinism. Overall, the myths were mostly derogatory and portrayed albinism in a very negative way. Some myths include persons with albinism are descended from gods or have some other supernatural ability. Other communities also believed albinism was transferred through contact. Such beliefs induce negative perceptions and behaviours towards persons with albinism.

In contrast to community perceptions, persons with albinism understood the condition as a natural condition or a genetic condition. Others held more positive views and thought of albinism as a blessing or gift from God. This description reveals that PWA can discard the negative community views and develop a healthy image of themselves. In 2021, Taylor et al., concluded that while other interpretations may persist, framing albinism through a biomedical lens helps to perceive children with albinism as persons with a genetic condition, which can lead to increased social acceptance. Participants, however, did not dismiss the disabling health challenges, such as eye and skin problems associated with albinism.

The derogatory myths and beliefs held by some communities lead to practices that discriminate against persons with albinism. Some of the discriminatory practices include mocking or teasing directed at PWA, social and community rejection, where people avoid PWA in the community or in some communities, they are denied access to the community entirely. Others associate albinism with the inability to be productive and, therefore, unjustly deny them job opportunities and positions.

Persons with albinism experience several unique challenges. These arise from different facets of their lives. It includes economic, health and health system-related, social, educational, environmental and outright human rights violations. The economic difficulties mainly result from unemployment and limitations on the sources of income available**.** Educational challenges emerge as school authorities are unaware of the needs of persons with albinism in their institutions. Additionally, the lack of support for students with visual impairment hinders learning and ultimately leads to poor performance in school**.** Health challenges are related mainly to visual and dermatological problems. Participants also perceived prejudicial treatment from some health workers that prevented them from receiving the necessary remedies they sought. Tambala-Kaliati, Adomako and Frimpong-Manso, (2021) also noted the report of prejudicial attitudes from health workers while conducting a phenomenological study in Malawi involving persons with albinism.

Climate elements such as the degree of solar radiation in a location directly affect the health of persons with albinism, particularly skin disorders, including skin cancer. This represents a challenge posed by their physical environment. Social challenges arise as difficulties in making friends and establishing meaningful relationships, and can lead to isolation. Threats to the safety and life of persons with albinism develop from beliefs and myths about utilising PWA in rituals for money or other nefarious purposes. This constitutes a serious human rights violation that requires immediate attention.

It is interesting to note that the challenges of persons with albinism are related in various ways that can often amplify a particular challenge. For example, educational challenges, stigmatisation and discrimination in schools can limit future career opportunities and, therefore, can limit potential sources of income and economic challenges. Again, financial difficulties may be a barrier to accessing quality healthcare to address health challenges.

Another important finding is the role of the support systems exploited by persons with albinism. Several participants had interacted with NGOs that had interventions or programs targeted at the albinism community. The programs include albinism education and awareness campaigns, eye and skin screening services and livelihood support initiatives that provide financial aid to cover educational expenses and healthcare costs. These programs help equip PWAs with the knowledge to make lifestyle choices that improve or reduce health risks, such as applying sunscreen for skin protection. The interventions assist persons with albinism in coping with the difficulties they experience. In addition, these initiatives provide opportunities to network, obtain mentorship and guidance from other members of the albinism community and their supporters.

Participants also emphasised the role of family acceptance and support in coping with the challenges. Family members and friends aided them by providing encouragement, emotional and financial support. Some admitted that family members struggled initially to accept them; however, with time, they gained some understanding of the condition and accepted them as family. Others were not as welcomed by their family, and this led to some unfortunate encounters and strained relationships. These findings are similar to those reported in other studies about albinism in African countries.

5.2 Interpretation of findings

5.2.1 Perceptions of Albinism

Perceptions of albinism in Ghana are largely influenced by myths and beliefs perpetuated in the different communities. These myths form somewhat of a lens through which persons with albinism are viewed. The origin of these beliefs is not so clear, but they seem to have been passed from one generation to another like other myths, without any evidence for these assertions. Some of these misconceptions possibly arise from a misunderstanding of the traits associated with albinism (Kajiru et al., 2020). A similar finding was reported by Kajiru (2020), in a study done in Tanzania. It demonstrated that these beliefs have endured through history and continue to impact PWA to this present day. For example, the visual impairment experienced by some PWA may have generated the myth that persons with albinism are blind or cannot see at night. Unfortunately, due to the largely negative myths about albinism, the perception of albinism by individuals in the community is mostly unfavourable. This phenomenon, promoted by the myths, is similar to that reported in literature on albinism in other African countries (Kromberg and Kerr, 2025; Bradbury-Jones et al., 2018). Consequently, most daily interpersonal interactions between PWAs and other individuals in these communities are not healthy. From this study, it usually takes the form of teasing or mocking, rejection or avoidance of persons with albinism. This is the experience reported by most participants, among peers at school during childhood and among adults in the community setting. This isolates them and deprives them of the basic healthy social interactions essential to the emotional and mental health of humans. A 2017 United Nations General Assembly report recognised the social development challenges of persons with albinism, focusing particularly on women and children. The report demonstrated the same findings concerning interactions with persons with albinism, leading to social exclusion and limited access to social amenities, especially in Africa. Following these findings, the UN has sought to institute programs to make impactful changes.

Perceptions held by the community are also evident at the institutional levels. For instance, in schools at all levels of education, students with albinism often do not receive the needed support to facilitate learning. They are erroneously considered less competent than colleagues for no reason other than their skin tone. Additionally, visual challenges make reading from the classroom board, projected screens, books and other reading materials difficult and therefore hinder learning. This challenge further reinforces the perception of limited competence as grades are subsequently affected. Osborne et al. (2025) explored vulnerable student populations, noted that students with albinism experienced high levels of discrimination from peers and had difficulties making friends in school. They described how students felt excluded and usually dropped out of school as a result. However, the study did not categorise students with albinism among persons with disabilities, possibly ignoring the biological challenges that affect their experience at school. Awareness of these challenges by school authorities may help understand the support needs of students with albinism and emphasise the importance of sensitisation and awareness creation campaigns (Maunganidze, Machiha and Mapuranga, 2022).

A similar occurrence is also observed at workplaces. Participants reported instances where they felt discriminated against at job interviews or by colleagues at the workplace. Employers invite people to interview but often reject them when they realise they are persons with albinism. Again, the perception of limited competency also influences employers' decisions to hire a person with albinism. Others reported that colleagues had workplace meetings without inviting them or made comments that undermined their abilities. This finding highlights the pervasiveness of the myths in Ghanaian communities and how they affect interactions at the community and institutional levels. Another study by Chu et al., (2021) surveyed the views of both PWA and non-PWA in Botswana. They discovered that although unemployment was present in both groups, it was higher among PWA. Persons with albinism relied mostly on family and government welfare as a source of government support. They also described how educational challenges limited opportunities for meaningful employment.

In contrast to public perceptions, persons with albinism hold different views on albinism. Participants accept and understand albinism as a natural condition and disregard the largely negative spiritual or supernatural beliefs about albinism perpetuated in their communities. Taylor et al., in 2021, hinted at this in a qualitative study on the reactions to the birth of a baby with albinism. They discovered that framing albinism as a genetic condition made it more acceptable to parents of PWA. However, this study did not include the interpretations of albinism by PWA. This is one of the ways this research is unique, in that it offers a glimpse of the perceptions of PWA about albinism. There seems to be a gap in self-perspective studies exploring the views PWA have developed about albinism amid negative community perceptions.

Despite the misconceptions in the community, it is important for persons with albinism to understand the condition. This empowers them to educate their families and community to dispel these beliefs**.** Again, they can make healthier lifestyle choices, such as choosing to wear sun protective clothing to reduce exposure to solar radiation. Ultimately, perceiving albinism as a unique, natural feature means a more positive self-image develops and can alleviate some of the supposed limitations associated with albinism, such as limited competence or ability. This finding has not been adequately explored in Ghana. Research in Africa has previously focused on community perceptions. However, this study also sheds more light on PWA's view of albinism.

It is interesting to note that many participants who had developed positive opinions about albinism had been involved in some way in sensitisation or awareness creation programs for albinism. These programs may have been instrumental in helping to develop these views amid the negative community perceptions. Although there is limited research on these findings, several newspaper articles on interviews with persons with albinism reveal that many successful or popular PWA reject harmful mystical beliefs and describe albinism as capable humans (Johnson, 2023).

5.2.2 Challenges and Barriers of Persons with Albinism

Discriminatory practices abound in places where community perceptions of albinism are unfavourable. These practices often exacerbate the challenges of persons with albinism. This study identified several unique challenges encountered by persons with albinism. These interact in different ways to amplify or reinforce the problem. The challenges can be categorised as health, educational, economic, social, environmental and human rights violations. Similar challenges are described in many other studies (Phatoli, Bila and Ross, 2015).

The health challenges, in particular, affect individuals in varying degrees. Therefore, persons with albinism have different experiences of health challenges. The major health challenges include visual impairment and skin disorders following exposure to solar radiation. Some participants with significant visual impairment had problems in school, reading from blackboards or projected presentations and reading materials available to them. This often led to faltering grades as school authorities failed to recognise the challenge and attempt to assist them. This establishes the link between the health challenges and educational challenges. Chu et al., (2021) also described how educational challenges limited opportunities for meaningful employment in the future. This was thought to be due to uncorrected visual impairments that limited the benefits of enrolment in school.

Another health problem that can also impact economic challenges and limit potential sources of income is the skin disorders precipitated by sun overexposure. For example, persons with albinism are unable to venture into petty trading or farming themselves, as it usually requires spending long periods under the sun. Doing so increases the potential for skin cancer as an occupational hazard. It implies that PWA must be selective in the type of job they venture into, therefore limiting potential income sources. A study by Carew et al. (2023) investigating the impact of climate change on the health of persons with albinism noted that the presence of barriers to suitable employment for PWA may lead to them opting for outdoor occupations such as farming or street vending. Investigators reiterated that working outdoors, coupled with the changing climate patterns, significantly increased the risk of skin disorders and skin cancer in persons with albinism. Additionally, they are often unable to purchase sunscreen products to protect themselves.

The health challenges are also evident at higher levels of the socioecological paradigm. Participants reported incidents with health workers who ignored their medical complaints, treated them harshly, or were ignorant of albinism and the needs of persons with albinism. This suggests that even in the professional environment, health workers still retain negative perceptions of albinism that influence their professional conduct. It constitutes an institutional or systemic health problem for persons with albinism. An article published by a reputable Ugandan agency in 2025 reported an interview with a PWA who was ignored when they complained of severe pain following surgery. Health workers failed to address her complaints and therefore resorted to visiting a private facility in the hope of better care there. From this study, many participants reported similar circumstances, with many of the negative treatments coming from public or government clinics or hospitals (Kannyange, 2025). Other studies in Ghana also show similar occurrences (Daklo and Obadire, 2024).

At the public policy level, accessing health care that addresses the unique ailments associated with albinism, such as ophthalmology and dermatology services, is also challenging. These services and medications needed are not covered under the Ghana National Health Insurance Scheme (NHIS). Ultimately, it deprives those unable to pay for these services and medicines of the needed medical care. In 2018, a study by Howard on the impact of the NHIS on persons with disabilities showed that there were significant barriers to accessing NHIA offices to register and a lack of coverage of needed eye care and skin care services. This study, though not specific to PWA, included all other persons with disabilities who face similar challenges.

Social challenges may be considered as another consequence of the myths and beliefs about albinism. Persons with albinism shared difficulties in forming and maintaining interpersonal relationships in their communities. This also includes finding and maintaining long-term romantic partnerships. The result of this is social isolation with its attendant psychological implications. This has been reported in other studies. Likumbo, de Villiers and Kyriacos, (2021) reported circumstances of marital breakdown when women delivered children with albinism, although neither parent was a person with albinism. Such women accepted the divorce and proceeded to care for their children on their own. Tambala-Kaliati, Adomako and Frimpong-Manso (2021) agreed with this from their study, as some PWA had difficulty establishing stable marriages. Another study also suggested that females had greater difficulty finding partners due to the fear and distrust of potential partners who may use them for money-making rituals (Daniel, 2015).

Economic constraints represent another area where challenges persist for persons with albinism. As previously discussed, limited potential sources of income have repercussions that affect an individual's ability to access health, further their careers and maintain livelihoods. Again, negative perceptions about albinism, even in the corporate and other working environments, mean PWAs are often overlooked when hiring employees. A study by

Maunganidze, Machiha and Mapuranga (2022) acknowledged the employment barriers faced by PWA. In addition to those mentioned in this study, they also highlighted the role biological limitations, such as visual impairment, play in restricting employment opportunities.

Human Rights

Persons with albinism also face human rights violations, as described by participants. These violations take the form of unlawful restrictions on movement within the community, denial of entry into some communities, threats to life and ritual killings for wealth. Almost all of these are motivated by cultural beliefs and myths about albinism that are passed from one generation to another (Owusu, 2024). The violations persist as authorities and governing institutions fail to investigate and punish perpetrators. Agencies tasked with protecting the rights and freedoms of citizens, including persons with albinism, fail to function as they should. As mentioned earlier, the United Nations Convention on the Rights of Persons with Disabilities, of which Ghana is a signatory, states Ghana's legal obligations to protect and promote the rights of all persons with disabilities, including persons with albinism. Comments from participants and institutions such as GAPA suggest that this has yet to be appreciably enforced, leaving PWAs vulnerable to this form of abuse. It signifies that although public policy exists to protect persons with albinism, implementation is still lacking.

5.2.3 Support for PWAs

Recognising the complexity of the challenges encountered, persons with albinism need support to overcome these hindrances to live fruitful and fulfilling lives. Although insufficient, some support is available through agencies and NGOs. Participants recounted how impactful some of the programs and interventions carried out were to them. These programs include sensitisation and awareness campaigns where the community was educated on albinism. Persons with albinism were also educated on the condition and how to cater for their health needs. Other interventions sought to provide PWAs with sun-protective materials such as sunglasses, long-sleeved shirts, wide-brim hats and sunscreen products. Another way support is given is by providing scholarships to further education, capital to set up sustainable businesses, and funds to cater for difficult health challenges such as skin tumours.

Assisting persons with albinism has also been facilitated by the establishment of the Ghana Association of Persons with Albinism (GAPA). GAPA organises PWAs to advocate for their interests and seek support for their needs. The organisation facilitates collaboration with other institutions seeking to support the albinism community. in this manner, PWAs are protected from exploitation and abuse by organisations. Institutions involved in assisting persons with albinism, among others, include Engage Now, Africa (ENA) and the Ghana Federation of Disability Organisations.

The support contributed by these organisations seems to be useful, as reported by participants who had been involved in the initiatives. They admitted that engaging in these programs was life-changing in different ways. For example, the sun protective items they were given helped them take better care of their skin to prevent skin disorders. It implies that well-planned programs and initiatives targeted at the albinism community are instrumental in improving the lives of persons with albinism.

Another benefit of these initiatives is that they serve as an avenue for persons with albinism to network, share experiences, to encourage and motivate each other to improve their lives. More experienced persons within the community can also become mentors for younger people and share their wisdom. For example, a participant recalled how they called on a health professional who is also a person with albinism to help dispel some myths she had been told about albinism. This encouraged them to continue working toward their goals. The role of these organisations, therefore, cannot be discounted in supporting persons with albinism in Ghana.

Apart from the contributions of organisations, acceptance and support from family members are particularly essential for persons with albinism. According to participants, acceptance from family enabled them to cope with some of the challenges they faced in their neighbourhood and community. it contributed immensely to their overall well-being. Family members defended, encouraged and motivated them to overcome negative treatment from colleagues at school and from the community members. The role of family represents an interpersonal level of influence in the lives of PWA.

In addition to family, not all community members had a negative attitude towards persons with albinism. Friends and colleagues at work who had also accepted them played a role in the support they received. They also contributed by encouraging and motivating them to attain their goals despite resistance.

Family members and friends also provided support in various ways. It includes financial and emotional support. Some participants recognised the assistance provided by schoolmates who shared their notes to help them overcome challenges at the secondary and tertiary education levels. Affram, Teye-Kwadjo and Gyasi-Gyamerah, (2019) explored the role of social support in the subjective well-being of PWA in Ghana. They found that social support partially mitigated the negative effect of stigma and discrimination on the subjective well-being of persons with albinism. They concluded that support for PWA is a reliable predictor of subjective well-being. This finding, therefore, supports the assertions from our research about the role of social support.

Unfortunately, not all PWAs have the benefits of family acceptance. For some, their presence creates tension within the family. In other instances, it may lead to the separation of the family. This finding is common in African countries, as reported by Aborisade (2021). The study reported on the childhood experiences of family violence against persons with albinism. They discovered that family prejudice against children with albinism leads to denial of educational and vocational sponsorship, cordial family relationships and exclusion from social events. Fortunately, difficulties do not always persist, as some families have been able to reconcile with time as awareness and understanding of albinism increase.

Ultimately, the support from organisations, family and friends helps persons with albinism to cope with the daily challenges associated with albinism. The support assists PWAs in developing both problem-focused and emotion-focused coping strategies. The activities of organisations help solve some of the physical problems of albinism, such as using sun protective strategies to reduce the risk of skin disorders (Gilaberte et al., 2022). Again, acceptance from friends and family contributes to the development of emotion-focused coping strategies, such as avoiding certain situations or seeking emotional support from family and friends (Fournier et al., 2025). All these interventions from organisations and contributions from family and friends culminate in an improved living experience for persons with albinism in Ghana. This suggests that despite the distasteful remarks from the community members, persons with albinism can still overcome challenges to have a positive self-image and high self-esteem.

Chapter 6 Conclusions and Recommendations

6.1 Conclusion

The findings of this research have provided information on the perspectives of PWA. Using the interview guide, we were able to understand the lived experiences of PWA, which include their perceptions, the challenges and barriers they face and the available support systems. It's important that we understand oculocutaneous albinism as a genetic disorder that presents with abnormal melanin pigmentation resulting in visual, skin disorders and stigmatisation. The main findings from this study revealed that there are still deeply rooted myths, misconceptions, and cultural beliefs that influence the negative perceptions about albinism, mainly through traditional beliefs and inadequate education. The negative experiences PWA are subjected to, including physical violence, are a violation of human rights and freedoms. Since genetic conditions often cannot be changed or altered, persons with albinism must be accepted and supported to overcome their challenges. The existence of the Persons with Disability Act (Act 715) in Ghana has provided an avenue for PWA to seek, receive the needed support and protection from abusers.

Application of the socioecological model to the perspectives of persons with albinism helps to understand the experiences of PWA in a structured manner. It provides opportunities for intervention that may be more effective and impactful. This study suggests supporting PWA may be more effective with a multi-level intervention approach. An important observation is that, in contrast to the negative community views, PWA had positive perceptions of albinism. They accepted it as a genetic condition that could not be cured, despite various challenges faced with access to basic human amenities such as healthcare, educational, economic challenges and others that significantly affect their quality of life.

Despite these challenges, the study also uncovered stories of resilience and strength, as many participants expressed determination to overcome societal barriers and advocate for change. This may be associated with exposure to sensitisation and awareness campaigns that empower persons with albinism. The realisation should garner support for more campaigns for the benefit of the albinism community. A better understanding of this may arise from the evaluation of previous albinism directed interventions.

Lastly, Family acceptance, religious leaders, traditional authorities and educators play a major role in the overall well-being of PWAs. The study revealed that public health campaigns on albinism were insufficient. Creating awareness about albinism at multiple levels is very important to promote inclusion and reduce stigma.

6.2 Recommendations

It is recommended that the government, NGOs and other civil societies take up and promote more sensitisation and awareness campaigns. In addition to community education programs, sensitisation must also be targeted at institutions like schools and universities, and at policymakers.

6.2.1 Recommendations for addressing albinism myths and perceptions

Monthly Radio Programs in Local Dialects

District Information Services Departments should run monthly radio shows on community stations to address albinism myths and promote acceptance. Inviting persons with albinism to share their personal stories can humanise their experiences and reduce harmful stereotypes.

Engagement of Traditional and Religious Leaders

Organize short workshops for chiefs, queen mothers, pastors, and imams on the biological basis of albinism and their role in reducing stigma. These leaders can then serve as ambassadors for inclusion and help shift harmful narratives in their communities.

Creation of Local Albinism Support Clubs

District Assemblies should help set up community-based support clubs for people with albinism and their families. These clubs can offer peer mentoring, emotional support, and training in self-advocacy, which is especially empowering for young people with albinism.

6.2.2 Recommendations to improve the livelihood of PWA

Provision of Free or Subsidised Sunscreen and Protective Gear

The Ministry of Health, in partnership with NGOs, should provide PWAs with free or affordable sunscreen, wide-brimmed hats, and UV-protective clothing through public hospitals and CHPS compounds. This reduces their risk of skin cancer and promotes physical comfort in Ghana’s sunny climate. These products, particularly sunscreen in addition to dermatological services, may be incorporated into the products and services covered by the National Health Insurance Scheme

Training PWA to Take Advantage of Technology

One avenue for income generation is training of PWA to use technology and social media. PWA can be trained in digital marketing, establishing online stores to market products, and other information technology-related jobs. These are opportunities to make a living without the risks of outdoor sun exposure.

Scholarship Opportunities and Visual Aid Support

The Ministry of Gender, Children and Social Protection should collaborate with the Ghana Scholarship Secretariat to create a small scholarship quota for students with albinism. Schools should also be supported with magnifying tools, larger print books, or permission for students with albinism to sit closer to the board.

Recommendations for Persons with Albinism

Persons with albinism can use available resources (e.g. internet) to study and understand the albinism condition. This will help develop habits or strategies to improve and maintain their health. It would also help them educate family members and friends about the condition and needs of persons with albinism.

Further Research

Albinism-targeted interventions should also be evaluated to determine their impact and refine them for better outcomes. This can be achieved by engaging the albinism community to gather baseline data. The intervention events and procedures carried out by organisations should be well documented. Finally, the community can be interviewed to determine the impact of these programs on PWA and the community as a whole.

References

Aboagye, F. (2024) Ghana Association of Persons with Albinism pushes for greater inclusivity from government, Ghanaweb. Available at: https://www.ghanaweb.com/GhanaHomePage/NewsArchive/Ghana-Association-of-Persons-with-Albinism-pushes-for-greater-inclusivity-from-government-1935777 (Accessed: 16 March 2025).

Aborisade, R.A. (2021) '"Why Always me?": Childhood Experiences of Family Violence and Prejudicial Treatment against People Living with Albinism in Nigeria', Journal of Family Violence, 36(8), pp. 1081–1094. Available at: https://doi.org/10.1007/S10896-021-00264-7,.

Adelakun, O.S. and Ajayi, M.-A.O. (2020) 'Eliminating Discrimination and Enhancing Equality: A Case for Inclusive Basic Education Rights of Children with Albinism in Africa', Nigerian Journal of Medicine, 29(2), pp. 244–251. Available at: https://www.ajol.info/index.php/njm/article/view/197544 (Accessed: 15 August 2024).

Affram, A.A., Teye-Kwadjo, E. and Gyasi-Gyamerah, A.A. (2019) "Influence of social stigma on subjective well-being of persons with albinism in Ghana," *Journal of Community and Applied Social Psychology*, 29(4), pp. 323–335. Available at: https://doi.org/10.1002/CASP.2403.

Africa Albnisim Network (2024) Ghanaian authorities too slow in upholding the rights of persons with disabilities says UN Committee - Africa Albinism Network. Available at: https://africaalbinismnetwork.org/blog/ghana-ghanaian-authorities-too-slow-in-upholding-the-rights-of-persons-with-disabilities-says-un-committee/ (Accessed: June 13, 2025)

Algorani, E.B. and Gupta, V. (2024) ‘Coping Mechanisms’, in *StatPearls*. Treasure Island (FL): StatPearls Publishing. Available at: http://www.ncbi.nlm.nih.gov/books/NBK559031/

Anshelevich, E.E., Mosojane, K.I., Kenosi, L., Nkomazana, O. and Williams, V.L. (2021) ‘Factors affecting quality of life for people living with albinism in botswana’, Dermatologic clinics, 39(1), pp. 129–145. Available at: https://doi.org/10.1016/J.DET.2020.08.012.

Republic of Ghana. (2006) Persons with Disability Act, 2006 (Act 715). Accra: Date of Assent: 9 August 2006. Gazette Notification: 11 August 2006.

Benyah, F.E.K. (2022) ‘Are albinos people like us? Albinism and social exclusion in Ghana’, in A.A. Alemanji, C.M. Meijer, M. Kwazema, and F.E.K. Benyah (eds) Contemporary Discourses in Social Exclusion. Cham: Springer International Publishing, pp. 143–170. Available at: https://doi.org/10.1007/978-3-031-18180-1_7.

Benyah, F. (2017) “Equally able, differently looking: discrimination and physical violence against persons with albinism in Ghana,” Journal for the Study of Religion, 30(1), pp. 161–188. Available at: https://doi.org/10.17159/2413-3027/2017/v30n1a7.

Biggs, A., Brough, P. and Drummond, S. (2017) ‘Lazarus and Folkman’s Psychological Stress and Coping Theory’, The Handbook of Stress and Health, pp. 349–364. Available at: https://doi.org/10.1002/9781118993811.CH21.

Bradbury-Jones, C., Ogik, P., Betts, J., Taylor, J. and Lund, P. (2018) ‘Beliefs about people with albinism in Uganda: A qualitative study using the Common-Sense Model.’, *PloS one*, 13(10), p. e0205774. Available at: https://doi.org/10.1371/journal.pone.0205774.

Braun, V. and Clarke, V. (2023) ‘Thematic analysis.’, APA handbook of research methods in psychology: Research designs: Quantitative, qualitative, neuropsychological, and biological (Vol. 2) (2nd ed.)., pp. 65–81. Available at: https://doi.org/10.1037/0000319-004.

Brocco, G. (2016) ‘Albinism, stigma, subjectivity and global-local discourses in Tanzania’, Anthropology and Medicine, 23(3), pp. 229–243. Available at: https://doi.org/10.1080/13648470.2016.1184009.

Carew, M.T., Keogh, M., Gliksohn, A., Mbuli-Robertson, S. and Miti-Drummond, M.A. (2023) ‘Unprotected: the consequences of climate change for the health of persons with albinism’, BMJ Global Health, 8(9), p. e013690. Available at: https://doi.org/10.1136/BMJGH-2023-013690.

Carr, D. and Pudrovska, T. (2007) ‘Mid-Life and Later-Life Crises’, Encyclopedia of Gerontology, pp. V2-175-V2-185. Available at: https://doi.org/10.1016/B0-12-370870-2/00126-8.

Chu, B., Maranga, A., Mosojane, K.I., Allen-Taylor, L., Ralethaka, M., Ngubula, J.C., Shifa, J.Z., Jereni, B.H., Nkomazana, O. and Williams, V.L. (2021) ‘Sociodemographic features of a cohort of people living with albinism in Botswana’, JAAD International, 2, p. 153. Available at: https://doi.org/10.1016/J.JDIN.2020.12.002.

Cruz-Inigo, A.E., Ladizinski, B. and Sethi, A. (2011) ‘Albinism in Africa: stigma, slaughter and awareness campaigns.’, *Dermatologic clinics*, 29(1), pp. 79–87. Available at: https://doi.org/10.1016/j.det.2010.08.015

Daklo, A.K. (2021). Access to healthcare for persons with albinism in Ghana ; A human rights approach.

Daklo, A. K. and Obadire, O. S. (2024) ‘Exploring the experiences of persons living with albinism in Ghana’, Cogent Education, 11(1). doi: 10.1080/2331186X.2024.2335792.

Daniel, A. (2015) ‘Socio-cultural conception of albinism and sexuality challenges among persons with albinism (PWA) in South-West, Nigeria’, AFRREV IJAH: An

International Journal of Arts and Humanities, 4(2), pp. 189–208. Available at: https://doi.org/10.4314/IJAH.V4I2.14.

Dapi, L.N., Tambe, B.A. and Monebenimp, F. (2018) 'Myths surrounding albinism and struggles of persons with albinism to achieve human rights in Yaoundé, Cameroon', Journal of Human Rights and Social Work, 3(1), pp. 11–16. Available at: https://doi.org/10.1007/S41134-018-0048-5/METRICS.

Dery, R. (2023) Persons with albinism still face discrimination - GAPA | Ghana News Agency. Available at: https://gna.org.gh/2023/06/persons-with-albinism-still-face-discrimination-gapa/#utm_source=chatgpt.com (Accessed: June 12, 2025).

Doris, F. (2019) 'Myths and Stereotypes: The lived experiences of people with albinism', Psychology and Behavioural Sciences, 8(3), p. 61. Available at: https://doi.org/10.11648/J.PBS.20190803.11.

Engage Now Africa (2023) Advocating for people with albinism in Ghana. Engage Now Africa, 18 November. Available at: https://engagenowafrica.org/2023/11/16705/ (Accessed: 2 November 2025).

Engage Now Africa (2016) Creating Albinism Awareness, One Community at a Time. 13 September. Available at: https://engagenowafrica.org/2016/09/creating-albinism-awareness-one-community-at-a-time/

Ero, I. (2021) Witchcraft killings of people with albinism rose during pandemic – UN expert | OHCHR. Available at: https://www.ohchr.org/en/press-releases/2021/07/witchcraft-killings-people-albinism-rose-during-pandemic-un-expert?LangID=E&NewsID=27346 (Accessed: 4 November 2024).

Federico, J.R. and Krishnamurthy, K. (2023) 'Albinism', StatPearls [Preprint]. Available at: https://www.ncbi.nlm.nih.gov/books/NBK519018/ (Accessed: 25 February 2025).

Fournier, H., Calcagni, N., Morice-Picard, F. and Quintard, B. (2023) ‘Psychosocial implications of rare genetic skin diseases affecting appearance on daily life experiences, emotional state, self-perception and quality of life in adults: a systematic review’, Orphanet journal of rare diseases, 18(1). Available at: https://doi.org/10.1186/S13023-023-02629-1.

Fournier, H., Pillaud, N., Morice-Picard, F., Hadj-Rabia, S., Arveiler, B. and Quintard, B. (2025) ‘Dyadic adjustment of persons with albinism and their significant other: A Bayesian mediation model of the Actor-Partner Interdependence (APIMeM)’, Social Science and Medicine, 367. Available at: https://doi.org/10.1016/j.socscimed.2025.117684.

Franklin, A., Lund, P., Bradbury-Jones, C. and Taylor, J. (2018) ‘Children with albinism in African regions: their rights to “being” and “doing”’, BMC international health and human rights, 18(1), p. 2. Available at: https://doi.org/10.1186/s12914-018-0144-8.

Ghana Association of Persons with Albinism (GAPA) (2019) Ritual banishment and stigmatisation of persons with albinism in Ghana: A contextual analysis report. Available at: https://africaalbinismnetwork.org/wp-nacontent/uploads/2022/09/1564577071633r4nwvrgc26e-1.pdf

Ghana Statistical Service, 2021. 2021 Population and Housing Census: Summary Report of Final Results. Accra: GSS.

Ghana Tourism Authority, 2019. Tourism Sites and Attractions in the Volta Region. Accra: GTA.

Gilaberte, Y., Mzumara, T.E., Manjolo, S.P., Kaseko, N., Bagazgoitia, L., Fuller, L.C. and Soto, M. (2022) ‘Evaluation of the acceptance and efficacy of a bespoke sun protection package for persons with oculocutaneous albinism living in Malawi’, International

Journal of Dermatology, 61(3), pp. 352–360. Available at: https://doi.org/10.1111/IJD.15793,.

Grønskov, K., Ek, J. and Brondum-Nielsen, K. (2007) ‘Oculocutaneous albinism.’, Orphanet journal of rare diseases, 2, p. 43. Available at: https://doi.org/10.1186/1750-1172-2-43.

Hong, E.S., Zeeb, H. and Repacholi, M.H. (2006) ‘Albinism in Africa as a public health issue’, BMC public health, 6, p. 212. Available at: https://doi.org/10.1186/1471-2458-6-212.

Howard, H.A. (2018) ‘The impact of the national health insurance scheme on the lives of persons with disabilities in Kumasi Metropolis, Ghana’, Disability, CBR & Inclusive Development, 29(3), pp. 93–104. Available at: https://doi.org/10.5463/DCID.V29I3.758.

ssJohnson, S. (2023) ‘A fire inside me’: the Zambian singer who overcame prejudice to change attitudes to albinism | Albinism | The Guardian, The Guardian. Available at: https://www.theguardian.com/global-development/2023/sep/13/a-fire-inside-me-the-zambian-singer-who-overcame-prejudice-to-change-attitudes-to-albinism?utm_source=chatgpt.com (Accessed: 27 June 2025).

Kajiru, Ines, Nyimbi, Isaack, Kajiru, I and Nyimbi, I (2020) ‘The impact of myths, superstition and harmful cultural beliefs against albinism in Tanzania: A Human Rights Perspective’, *Potchefstroom Electronic Law Journal*, 23(0), pp. 1–27. Available at: https://doi.org/10.17159/1727-3781/2020/v23i0a8793.

Kannyange, M.J. (2025) Discrimination in Ugandan hospitals hurts, persons with albinism say | Monitor, Daily Monitor, Uganda. Available at: https://www.monitor.co.ug/uganda/news/national/discrimination-in-ugandan-hospitals-hurts-persons-with-albinism-say--5078774?utm_source=chatgpt.com (Accessed: 21 July 2025).

Katowa, P., Mwape, L., Maimbolwa, M., Muleya, C. and Beauty, N. (2015) ‘International Journal of Psychology and Counselling Stress and coping with cervical cancer by patients: A qualitative inquiry’, 7, pp. 94–105.

Kromberg, J.G.R., Flynn, K.A. and Kerr, R.A. (2023) ‘Determining a worldwide prevalence of oculocutaneous albinism: A Systematic Review’, *Investigative Ophthalmology & Visual Science*, 64(10), pp. 14–14. Available at: https://doi.org/10.1167/IOVS.64.10.14.

Kromberg, J.G.R. and Kerr, R.A. (2025) ‘Albinism research in a Southern African setting: unique findings’, Journal of Community Genetics, 16(2), pp. 107–116. Available at: https://doi.org/10.1007/S12687-025-00786-3/METRICS.

Likumbo, N., de Villiers, T. and Kyriacos, U. (2021) ‘Malawian mothers’ experiences of raising children living with albinism: A qualitative descriptive study’, African Journal of Disability, 10, p. 693. Available at: https://doi.org/10.4102/AJOD.V10I0.693.

Ma, E.Z., Zhou, A.E., Hoegler, K.M. and Khachemoune, A. (2023) ‘Oculocutaneous albinism: epidemiology, genetics, skin manifestation, and psychosocial issues’, *Archives of Dermatological Research*, 315(2), pp. 107–116. Available at: https://doi.org/10.1007/s00403-022-02335-1.

Macherera, C.T. and Tshuma, H. (2025) ‘The psychosocial impact of albinism on learners’ academic performance. A case of Reigate District in Bulawayo, Zimbabwe’, International Journal of Research and Innovation in Social Science, IX(III), pp. 466–473. Available at: https://doi.org/10.47772/IJRISS.2025.90300037.

Mangones, A. ‘Livelihoods and Food Security’, PrepareCenter. Available at: https://preparecenter.org/topic/livelihoods-and-food-security/ (Accessed: 1 August 2024).

Marçon, C.R. and Maia, M. (2019) ‘Albinism: epidemiology, genetics, cutaneous characterization, psychosocial factors’, *Anais Brasileiros De Dermatologia*, 94(5), pp. 503–520. Available at: https://doi.org/10.1016/j.abd.2019.09.023.

Masanja, M.M., Imori, M.M. and Kaudunde, I.J. (2020) ‘Lifelong agony among people with albinism (PWA): Tales From Lake Zone in Tanzania’, Journal of Social and Political Sciences, 3(2). Available at: https://doi.org/10.31014/aior.1991.03.02.172

Maunganidze, F., Machiha, K. and Mapuranga, M. (2022) ‘Employment barriers and opportunities faced by people with albinism. A case of youths with albinism in Harare, Zimbabwe’, Cogent Social Sciences, 8(1). Available at: https://doi.org/10.1080/23311886.2022.2092309.

Mouhari-Toure, A., Akakpo, S.A., Teclessou, J.N., Gnossike, P., Adam, S., Mahamadou, G., Kassang, P., Elegbede, Y., Darre, T., Kombate, K., Pitché, P. and Saka, B. (2021) ‘Factors associated with skin cancers in people with albinism in Togo’, Journal of Skin Cancer, 2021(1), p. 3433493. Available at: https://doi.org/10.1155/2021/3433493.

Meteorological Service Department of Ghana, 2020. *Climate Data for Volta Region*. Accra: MSD.

Ndomondo, E. (2015) ‘Educating children with albinism in Tanzanian regular secondary schools: challenges and opportunities’, International Journal of Education and Research, 3(6). Available at: www.ijern.com (Accessed: 27 February 2025).

Nebre, M. (2018) ‘Social discrimination against people with albinism’, A Journal of Exploratory Research and Analysis [Preprint].

Organisation for Economic Co-operation and Development (2021), Applying Evaluation Criteria Thoughtfully, OECD Publishing, Paris, https://doi.org/10.1787/543e84ed-en.

Osborne, A., Yillah, R.M., Bash-Taqi, A. and Conteh, O. (2025) ‘A study of vulnerable student populations, exclusion and marginalization in Sierra Leonean secondary schools: a social justice theory analysis’, BMC Psychology, 13(1), pp. 1–17. Available at: https://doi.org/10.1186/S40359-025-02554-X/TABLES/1.

Owusu, E.S. (2024) ‘Ritual Child Homicide in Contemporary Africa: A systematic review of the empirical literature’, International Criminal Justice Review [Preprint]. Available at: https://doi.org/10.1177/10575677241282014/SUPPL_FILE/SJ-DOCX-1-ICJ-10.1177_10575677241282014.DOCX.

Patricia, K.-M., Lonia, M., Margaret, M.C., Mutinta, M.C. and Beauty, N.L. (2015) ‘Stress and coping with cervical cancer by patients: A qualitative inquiry’, International Journal of Psychology and Counselling, 7(6), pp. 94–105. Available at: https://doi.org/10.5897/IJPC2015.0313.

Phatoli, R., Bila, N. and Ross, E. (2015) ‘Being black in a white skin: Beliefs and stereotypes around albinism at a South African university’, African Journal of Disability, 4(1), p. 10. Available at: https://doi.org/10.4102/AJOD.V4I1.106.

Reimer-Kirkham, S., Astle, B., Ero, I., Imafidon, E. and Strobell, E. (2022) ‘Mothering, albinism and human rights: the disproportionate impact of health-related stigma in Tanzania’, Foundations of Science, 27(2), pp. 719–740. Available at: https://doi.org/10.1007/S10699-020-09701-0/METRICS.

Setordjie, I. (2024) International Albinism Awareness Day: GAPA calls for inclusion of albinism healthcare products on National Health Insurance Scheme. Available at: https://www.myjoyonline.com/international-albinism-awareness-day-gapa-calls-for-inclusion-of-albinism-healthcare-products-on-national-health-insurance-scheme/

Strength Beyond All Odds… People with Albinism | EEAS (2021). Available at: https://www.eeas.europa.eu/eeas/strength-beyond-all-odds%E2%80%A6-people-albinism_en (Accessed: 24 February 2025).

Tambala-Kaliati, T., Adomako, E.B. and Frimpong-Manso, K. (2021) 'Living with albinism in an African community: exploring the challenges of persons with albinism in Lilongwe District, Malawi', Heliyon, 7(5), p. e07034. Available at: https://doi.org/10.1016/j.heliyon.2021.e07034.

Taylor, J., Bradbury-Jones, C., Ogik, P., Kawuma, F., Betts, J. and Lund, P. (2021) 'Reactions to and explanations for the birth of a baby with albinism: a qualitative study in Busoga, Uganda', BMJ Open, 11(2), p. e040992. Available at: https://doi.org/10.1136/BMJOPEN-2020-040992.

United Nations (2015) General Assembly (GA) | Division for Inclusive Social Development (DISD). Available at: https://social.desa.un.org/publications/general-assembly?f%5B0%5D=ga-year%3A2014 (Accessed: 16 March 2025).

United Nations General Assembly, Social development challenges faced by persons with albinism, A/72/169, 19 July 2017, https://www.refworld.org/reference/themreport/unga/2017/en/118199 [accessed 26 June 2025]

United Nations (2019) Independent Expert on the enjoyment of human rights by persons with albinism. Available at: https://docs.un.org/en/A/74/190 (Accessed: 28 February 2025).

'Uromi Sabbath M. 'Violence against persons with albinism and older' (2014). Available at: https://www.ijern.com/journal/June-2014/25.pdf (Accessed: 15 August 2024).

Wright, C.Y., Norval, M. and Hertle, R.W. (2015) 'Oculocutaneous albinism in sub-Saharan Africa: adverse sun-associated health effects and photoprotection', Photochemistry and photobiology, 91(1), pp. 27–32. Available at: https://doi.org/10.1111/PHP.12359.

Appendix

Appendix 1: Interview Guide

Perspective of People Living with Albinism in Ghana

Persons with albinism (lived experiences/engagement with ENA)

Background/ Demographics

1. Could you briefly introduce yourself?

(Age, education, occupation, educational level, marital status)

2. How would you describe albinism in your own words?

3. Are there any myths about albinism in your community? How have these beliefs affected you? (Is it a taboo? Sacrifice for money rituals, for rains?)

4. In your opinion what steps could be taken to improve awareness about albinism?

Lived Experiences

5. What is it like to live in your community as a person with albinism?

6. What are some of the challenges you encounter? (social, economic, health)

7. Have you experienced discrimination or stigma related to your condition? If so, can you share?

8. How do community members generally relate with persons with albinism? (, peers, or colleagues, family members).

9. When and how did you first become aware of your condition?

Coping Strategies

10. How do you cope with the challenges you face? (Reconnect with challenges mentioned before)

11. Have you received support from family, friends, or organizations? If so, what kind of support and which one has been most helpful? (what kind of support and from which specific group?) Probes: Do you receive LEAP, any community services in your community? (Are there any special favours you've had in your community related to your condition?).

12. How do you take care of your health needs related to skin protection and vision care? (Caps, sunscreen, glasses, hospital visits, regularity of hospital visits, protective clothing).

13. Are there specific resources or services in your community that you find helpful?

14. Are you aware of any organizations or initiatives that support persons with albinism? If so, names of organizations, and in what way have they supported the persons with albinism?

Engagement with Engage Now Africa

15. How did you first get involved with Engage Now Africa?

16. For how long did you participate in the project?

17. In what ways has Engage Now Africa supported you or your community?

18. What programs or initiatives have you participated in?

19. How have they impacted your life? (Self-confidence, acceptance, career advancement)

20. What changes have you made in your life as a result of participating in ENAs activities?

21. How did *your* participation in the project affect your household?

22. Which aspects of the project were relevant/helpful to you?

23. Which aspects of the project were relevant to other persons in your household (children, etc.)

24. Are there any areas where you feel Engage Now Africa could improve or expand its support for persons with albinism?

Future Aspirations

25. What changes would you like to see in your community regarding the treatment and inclusion of persons with albinism?

26. What are your personal aspirations for the future, both for yourself and for the albinism community?

27. How can organizations like Engage Now Africa support these aspirations?

28. What will you ask ENA to do differently regarding their interventions?

29. What message would you like to share with the general public about albinism?

Additional Thoughts

30. Is there anything else you would like to share about your experiences that we haven't covered?

31. What advice would you give to someone newly diagnosed with albinism or facing similar challenges?

Thank you very much for your time. We appreciate it.

Appendix 2: Consent Form

Study Title: Evaluation of Albinism Projects: Perspective of People Living with Albinism in Selected Regions in Ghana

Principal Investigator:

Affiliation: Ensign Global College

Introduction

You are being invited to participate in a research study that seeks to explore the experiences and coping strategies of persons living with albinism in Ghana. The study aims to understand the challenges faced by persons with albinism (PWA) and the ways in which they manage these challenges in their daily lives. Before deciding to participate or not, it is important that you understand the purpose of the study, what it will involve, and your rights as a participant.

Purpose of the Study

The purpose of this study is to gain an in-depth understanding of the experiences of persons living with albinism in Ghana, particularly focusing on how they cope with the social, economic, health-related and other challenges they encounter.

Procedures

If you agree to participate in this study, you will be asked to take part in a semi-structured interview that will last approximately 30 minutes. During the interview, you will be asked about your personal experiences, challenges, and the strategies you use to cope with these challenges. The interview will be audio-recorded to ensure accuracy in capturing your responses.

Risks and Discomforts

There are no major risks associated with participating in this study. However, discussing personal experiences may cause emotional discomfort. If you feel uncomfortable at any point, you are free to skip any questions or withdraw from the study without any consequences.

Benefits

While there may be no immediate benefit to you for participating in this study, your participation will contribute valuable insights that could help in improving the lives of persons with albinism in Ghana. The findings from this study may be used to inform policies, programs, and initiatives aimed at supporting PWA.

Confidentiality

All information you provide during the study will be kept confidential. Your name and any other identifying information will not be included in the study reports or publications. The audio recordings and transcripts will be stored securely and will only be accessible to the research team.

Voluntary Participation

Participation in this study is completely voluntary. You have the right to refuse to participate, to skip any questions, or to withdraw from the study at any time without any penalty or loss of benefits.

Contact Information

If you have any questions or concerns about this study, please feel free to contact the principal investigator, Philip Peprah at philip.peprah@st.ensign.edu.gh. If you have any questions about your rights as a research participant, you may contact Ensign Global College Ethics Review Board.

Consent

By signing below, you indicate that you have read and understood the information provided above and that you voluntarily agree to participate in this study.

Participant's Name: ___________________________

Participant's S Signature/ Thumbprint: ________________________

Date: ______________________________________

Researcher's Name: __________________________

Researcher's Signature/ Thumbprint: ______________________

Date: ______________________________________

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