



UNIVERSITY OF GHANA

**COLLEGE OF HUMANITIES**

**DEPARTMENT OF SOCIAL WORK**

**LIVED EXPERIENCES OF PERSONS WITH ALBINISM IN  
LILONGWE DISTRICT, MALAWI**

**BY**

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**THIS THESIS IS SUBMITTED TO THE UNIVERISTY OF GHANA, LEGON, IN  
PARTIAL FULFILMENT OF THE REQUIREMENTS  
FOR THE AWARD OF MASTER OF PHILOSOPHY  
DEGREE IN SOCIAL WORK**

**APRIL, 2020**

**DECLARATION**

This is to certify that this thesis is the result of research undertaken by Thandiwe Tambala - Kaliati towards the award of the Master of Philosophy degree in the Department of Social Work, University of Ghana. This research has not been submitted to any university for any award, and authors whose work have been cited have been duly acknowledged.



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## **DEDICATION**

This work is, firstly, dedicated to GOD ALMIGHTY, my Jesus Christ and the Holy Spirit, for the opportunity and privilege accorded me to undertake this study and for abundant grace granted to commence and end well. Again this work is dedicated to my husband, John Kaliati, my children Charlotte Akuzike, Wilfred Nyasha, Saoirse Sarah, my lovely prayer warrior mum Mrs. Magret Ndasowampangi and my Aunt Ellen Ndekha who supported me through thick and thin during the course of this work. This work is also dedicated to all persons with albinism in Malawi and beyond.

## **ACKNOWLEDGEMENT**

First and foremost, I would like to thank GOD who made this thesis a reality. I wish to express my indebtedness and sincere appreciation to my two supervisors Dr. Kwabena Frimpong-Manso and Dr. Doris Boateng, all of the Department of Social Work, for their guidance, supervision, objective criticisms, suggestions and corrections, which contributed immensely to the completion of this work.

I would like to thank all my participants - persons with albinism, Mr. Michael Mvula for their time and contributions to this study. I thank the management of Association of People with Albinism in Malawi (APAM), Kanengo in the Protection of Rights of People with Albinism (KAPRA) and Musical Crossroads – Malawi (MCM) for their contributions to this study. I acknowledge the physical and spiritual support and encouragement rendered to me by my best friend Clare Kyemuhondo and her late mum.

My deepest gratitude also goes to my husband for always being my source of strength, understanding and for providing financial and emotional support. Finally, I would like to appreciate all those who I did not mention by mistake, thank you all, I could not have made it without your support. God bless you all.

## ABSTRACT

Albinism is a genetic condition that is inherited from both parents due to a lack of or the complete absence of melanin in the bodies of persons with albinism (PWA). In Malawi, like any other country, persons with albinism are normally characterized by differences in skin and hair color, in addition to the wobbling of the eyes. This often leads to negative treatment from their family, the community and society. The lack of melanin and its accompanying effects limit their functionality because when exposed to the sun and strong light, some become short-sighted and are more prone to skin cancer and related lesions. This study examines the lived experiences of persons with albinism in Lilongwe District, Malawi, in order to identify the challenges that they face as well as their coping mechanisms. This is to ascertain recommendations in order to improve their living status. The study adopted a qualitative design and selected thirty participants from both rural and urban areas. The participants included persons with albinism and key informants from the Association of People with Albinism in Malawi (APAM), Kanengo in the Protection of Rights of People with Albinism (KAPRA) and Musical Crossroads – Malawi (MCM) from Lilongwe District. The data was collected through face to face in-depth interviews as well as focus group discussions. The data was subsequently analyzed using Van Manen's (1990) six steps of phenomenological analysis. The findings revealed that PWA encounter financial challenges because of frequent poor academic attainment which limits their employability. Because of the economic hardship, their health is compromised as they do not have the money needed to access proper medical care for their eyes and skin. These medical services are only available in the major hospitals in the cities. Considering this, the study recommends the provision of economic empowerment in the form of vocational training, donations and soft loans to aid these individuals when they are seeking to establish businesses that will allow them to work in the shade. This will help to boost their productivity and self-reliance.

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### LIST OF ABBREVIATIONS

<b>APAM</b>	:	Association of People with Albinism in Malawi
<b>COPOSO</b>	:	Contributing Positively to the Society
<b>CSO</b>	:	Civil Society Organizations
<b>DIWA</b>	:	Disability Women In Africa
<b>ECH</b>	:	Ethics Committee for the Humanities
<b>IAAD</b>	:	International Albinism Awareness Day
<b>JCE</b>	:	Junior Certificate Examination
<b>KAPRA</b>	:	Kanengo in the Protection of Rights of People with Albinism
<b>MCM</b>	:	Musical Crossroad Malawi
<b>MSCE</b>	:	Malawi School Examination Council
<b>NGO</b>	:	Non-Governmental Organization
<b>NOAH</b>	:	National Organisation for Albinism and Hypopigmentation
<b>OC</b>	:	Ocular Albinism
<b>OCA</b>	:	Oculocutaneous albinism
<b>PWA</b>	:	Persons with albinism
<b>SEPE</b>	:	Supporting Employability and Personal Effectiveness
<b>SPF</b>	:	Sun Protection Factor
<b>UN</b>	:	United Nations
<b>WHO</b>	:	World Health Organization

## ABSTRACT

Albinism is a genetic condition that is inherited from both parents due to a lack of or the complete absence of melanin in the bodies of persons with albinism (PWA). In Malawi, like any other country, persons with albinism are normally characterized by differences in skin and hair color, in addition to the wobbling of the eyes. This often leads to negative treatment from their family, the community and society. The lack of melanin and its accompanying effects limit their functionality because when exposed to the sun and strong light, some become short-sighted and are more prone to skin cancer and related lesions. This study examines the lived experiences of persons with albinism in Lilongwe District, Malawi, in order to identify the challenges that they face as well as their coping mechanisms. This is to ascertain recommendations in order to improve their living status. The study adopted a qualitative design and selected thirty participants from both rural and urban areas. The participants included persons with albinism and key informants from the Association of People with Albinism in Malawi (APAM), Kanengo in the Protection of Rights of People with Albinism (KAPRA) and Musical Crossroads – Malawi (MCM) from Lilongwe District. The data was collected through face to face in-depth interviews as well as focus group discussions. The data was subsequently analyzed using Van Manen's (1990) six steps of phenomenological analysis. The findings revealed that PWA encounter financial challenges because of frequent poor academic attainment which limits their employability. Because of the economic hardship, their health is compromised as they do not have the money needed to access proper medical care for their eyes and skin. These medical services are only available in the major hospitals in the cities. Considering this, the study recommends the provision of economic empowerment in the form of vocational training, donations and soft loans to aid these individuals when they are seeking to establish businesses that will allow them to work in the shade. This will help to boost their productivity and self-reliance.

## CHAPTER 1

### INTRODUCTION

#### 1.0 Background of the Study

Genetic disorders like albinism that are inherited from both parents are difficult to avoid, especially in cases where both parents do not have knowledge of their family history. Children have a higher chance of being born with albinism if both parents either have albinism or carry the gene. Albinism is a genetic condition caused by a deficit in the production of the pigment called melanin. This pigment protects the skin against ultraviolet light and provides the skin with its color production (Franklin et al, 2018). The condition occurs at birth and lasts across the life course. The level of melanin differs in persons with albinism and results in differences of appearance in terms of skin, hair color and eye movements. The condition may predispose persons with albinism to lifelong physical and health problems such as visual impairment and ultra-violet induced skin damage that can lead to skin cancer. In Malawi, these health problems are exacerbated by poverty, exposure to harsh sunlight and a reduced access to adequate health care, especially in rural areas (Lynch, Lund & Massah, 2014).

There are two major types of albinism namely oculocutaneous albinism (OCA) and ocular albinism (OC) with various subtypes (Kagore & Lund, 1995; National Organisation for Albinism and Hypopigmentation, 2014; Brocco, 2015). Oculocutaneous albinism is passed from one generation to another through the autosomal recessive gene, implying that there is a one in four likelihood that a baby will be born with OCA ([www.biomedcentral.com](http://www.biomedcentral.com)). Mutasa, (2013) cited Oetting et al., (1996) when stating that in ocular albinism (OA), the mothers carry the gene and pass it to their sons. This is because it involves two variants based on the inheritance pattern involved. One variant is autosomal recessive ocular that occurs in

both men and women. The other is X-linked ocular with the symptoms occurring mainly in men.

There are currently seven forms of oculocutaneous albinism (OCA) that are recognized. There are also subtypes. The pigment range of OCA varies from persons with no pigmentation at all to those with slight pigmentation with yellowish or brownish hair (Mutasa, 2013; NOAH, 2014). The most common form of albinism in Africa is oculocutaneous albinism (OCA) which affects the eyes, skin, and hair of a person. These individuals have little or no melanin. Ocular albinism (OA) affects the eyes only and it is much less common. However, there is melanin activity hence there is no clinical consequence regarding the pigmentation of the skin and hair (Oetting et al., 1996; Lund, 2005; Cruz-Inigo, Ladizinski, & Sethi, 2011; Kromberg et al., 2012; Wright, Norval, & Hertle, 2015). Clinically, four types of OCA have been examined and these are OCA1, OCA2, OCA3 and OCA 4.

OCA1 is regarded as the most severe type of albinism characterized by an absolute lack of melanin production. This is because the tyrosinase in the individual is dysfunctional. This is a crucial enzyme that is required in melanin production ([www.ncbi.nlm.gov](http://www.ncbi.nlm.gov)). The other types of OCA show a pigmentation deposition over time ([www.ncbi.nlm.gov](http://www.ncbi.nlm.gov)). Type 1 OCA with subtype 1A (OCA1A) is the severest type of albinism with no melanin production at all. This type of albinism is extremely rare in black Africans (Kromberg et al., 2012; Kamaraj & Purohit, 2014). Type 2 OCA2 is the most common form of albinism in sub-Saharan Africa (Kromberg et al., 2012). OCA2 involves tyrosinase which produces a red-yellow pigmentation that culminates in sandy-colored hair and light brown irises ([www.ncbi.nlm.gov](http://www.ncbi.nlm.gov)). Type 3 OCA3 is a form of albinism that is more common among black Africans but rare in other races. It is also known as Rufous OCA and individuals with this

form of albinism have a reddish-bronze skin color as well as hair lighter than their skin color, usually ginger-colored, with blue or brown eyes (Kromberg et al., 2012). Type 4 OCA4 involves physical features that are close to those of OCA2 where the hair color can range from yellow to brown depending on the amount of pigment that is present ([www.ncbi.nlm.gov](http://www.ncbi.nlm.gov)).

Globally, it is estimated that the prevalence rate of persons with albinism is 1 in 17,000. In Africa, the overall prevalence rate for albinism has been reported as 1:5000 (Wright, Norval & Hertle, 2015). In Malawi, currently there are 134,636 persons with albinism in the country of which 17,156 live in urban areas and 117,480 live in rural areas (Malawi Population and Housing Census, 2019). Nonetheless, with the current awareness and support for the rights of persons with albinism being undertaken by different stakeholders, the number of persons with albinism is expected to rise. It is unclear why the prevalence rate of persons with albinism is now so high, especially in rural areas. It may be due to the founder effect of some form of heterozygote advantage, local high consanguinity or high carrier rates (Lund & Roberts, 2018; Kromberg, 2018). In addition, it may be due to various factors such as cultural practices, whereby some traditions marry from the same blood lineage, as well as the availability of good health and support services (Lund, Maluleke, Gaigher, & Gaigher, 2007). Furthermore, as the nation's population increases, the prevalence rate of persons with albinism could increase across various geographical regions.

There is a growing recognition and acceptance in Africa that people with albinism should be considered disabled (Franklin, Lund, Bradbury-Jones, & Taylor., 2018). In Malawi, persons with albinism are considered to have disabilities because their circumstances limit their participation in daily activities. This is in line with the definition of disability as stated by the World Health Organization that implies disability to be an umbrella term covering

impairments, activity limitations and participation restrictions (WHO, 2011). Impairment refers to a loss in bodily function or structure. Activity limitation refers to the difficulty encountered by an individual when executing a task or action. Participation restriction refers to a problem experienced by an individual who is unable to be involved in the control of their life situation (Government of Malawi, 2012). However, according to Franklin et al (2018), it is debatable whether one can classify albinism as a disability since on an individual level, people may not necessarily accept or adopt such a label, especially those with ocular albinism who function without any physical or medical difficulties.

Persons with albinism suffer socially due to myths, attitudes, social exclusion, labeling and the beliefs that are associated negatively with their condition which lead to stigma and discrimination. As a result, persons with albinism are psychologically affected because of the injustice towards them. There are various studies that have reported on the violence and attacks against persons with albinism in some African countries (Cruz-Inigo et al., 2011; Ikuomola, 2015; Franklin et al, 2018). Many societies consider them to be mysterious, evil and incapable of doing what other persons without albinism can do (Small, 1998). In Zimbabwe, persons with albinism are viewed as belonging to a magical world capable of doing good or evil (Machoko, 2013). In Tanzania and Kenya, it is believed that PWAs have the potential to access the spiritual realm to bring good luck and to take away bad luck. This has contributed to the attacks and killings targeting persons with albinism (Nyamu, 2014; Burke, Kaijage, & John-Langba, 2014; Saffitz, 2018; Nkrumah, 2018). Due to the stigma associated with albinism, some families in South Africa and Zimbabwe have killed or left persons with albinism to die (Baker, Lund, Nyathi, and Taylor, 2010). It was reported by the BBC (2017) that persons with albinism in Nigeria have been sidelined when trying to secure jobs for which they were qualified because of their condition. In a study conducted by

Bradbury-Jones et al (2018), they investigated the beliefs, myths, traditions and attitudes that surround people with albinism in Uganda. They found that pigmented Ugandans were afraid of persons with albinism as they viewed them with suspicion and believed that they possess supernatural powers. In Ghana, persons with albinism suffer ridicule and labeling in schools and in the community due to the derogatory names labeling them such as “ofri,” meaning a “black person in a borrowed white skin” (Akomolafe, 2019).. This violation of their human rights, in addition to the isolation, labeling, belief stigma and discrimination due to their skin and hair color, makes the lives of persons with albinism miserable. The stigma and prejudice results in a limited access to equal opportunities and restricted choices when it comes to participation in the activities that can bring about social change.

For women with albinism, relationships are difficult because they often experience rejection by the men who may have wished to marry them, unlike men with albinism who freely find love and marry people without albinism without any discouragement from their family members. Generally speaking, the family members discourage marriage if it is to a woman with albinism. The situation gets even worse for women who give birth to children with albinism. Such women suffer a double tragedy as they are rejected by both their husbands and families based on the myth that the child was conceived with men of other races or men who are cursed, unclean and witches (Salewi, 2011). Children born with albinism are treated as outcasts. Unfortunate ones are killed at birth or as infants, and others are hidden from the public (Baker et al, 2010). Furthermore, Braathen and Ingstad (2006), in a qualitative study on the experiences of young persons with albinism in Malawi, found that the fathers rejected and abandoned their children. This may be because the family members of children with albinism were viewed as being responsible for the albinism. This is because albinism is

thought to result from past misdeeds within the family, such as the infidelity of the mother (Blankenberg, 2000).

In 2012, Malawi experienced a severe drought and poor harvest. Most households did not have food or a source of income to sustain their families. As a result, most households were struggling to make ends meet and they were in search of anything that could alleviate the economic and food crisis that they were facing. Strangers lured the relatives of persons with albinism and prompted them to harvest their body parts to make easy money and a better fortune to alleviate their suffering. Persons with albinism are thought to be a source of power due to their distinct look. The nation of Malawi was taken by surprise by the gruesome killings of persons with albinism in both its cities and rural areas. Weeks could not pass without hearing of a new case of PWA body harvesting, abduction, grave exhumation and attempted attacks. Malawi has one of the highest totals concerning such reports and attacks in the region. As of 2018, one hundred and forty eight (148) cases of murder, kidnappings and other albinism-related crimes were reported and seventeen (17) cases were ritual killings (Mostert & Weich, 2017; [www.actionalbinism.org](http://www.actionalbinism.org), 2019). In addition, it is believed that more cases have not been documented, especially those in rural areas. The killers abduct and kill persons with albinism and remove their eyes, breasts, feet and hands. These are sold to dealers in the neighboring country of Mozambique (Mostert & Weich, 2017). There are still yet more cases involving the killing and body part harvesting of persons with albinism, especially during election year. This is as some politicians believe that the body parts of persons with albinism will bring them electoral victory (Mail & Guardian newspaper, 2015; USS, 2017). In Malawi, the killing of a person with albinism which involved a police officer, a medical doctor and a Roman Catholic priest brought in a state of significant fear and insecurity for persons with albinism (Nyasatimes, 2018) who felt that the associated

institutions were supposed to be there to provide hope and security for them. The Convention on the Rights of Persons with Disabilities (Article 10) provides for their right to life and every States Party reaffirms that every human being has the inherent right to life as well. One should take all of the necessary measures to ensure its effective enjoyment by persons with disabilities which includes persons with albinism on an equal basis with others.

In a bid to find a global solution to the plight of persons with albinism, the worldwide media coverage and the intervention of the United Nations declared PWAs to be a special group with particular needs that require special attention and protection. This was adopted by the United Nations Human Rights Council as resolution 28/L.10. In addition, civil society organizations (CSOs) and academia have helped to bring to light the other social issues of concern regarding persons with albinism that were never taken into much consideration before (United Nations, 2015). The resolution created the mandate of an independent expert concerning the enjoyment of human rights by persons with albinism. This new mandate was enacted to give a voice to persons with albinism and to contribute to their protection through greater awareness raising, hence the creation of International Albinism Awareness Day. The first International Albinism Awareness Day (IAAD) was held on June 13<sup>th</sup> 2015 following a resolution put forward by the UN in 2014 (International Albinism Awareness, 2016). In light of the above, this study has explored the lived experiences of persons with albinism in Lilongwe District, Malawi. This study sought to identify the challenges faced, the coping mechanisms adopted and the recommendations put forward to improve their lives.

### **1.1 Statement of the Problem**

The plight of persons with albinism in Malawi remains a major concern of the nation. Challenges such as poverty, limited access to medical care, a lack of conducive learning environments and resources, a lack of community empowerment, limited participation in

community activities, discrimination and stigma all affect the wellbeing of persons with albinism (Nyamu, 2014). The lack of accurate numbers, systematic follow-ups and information on the whereabouts of persons with albinism makes it difficult for stakeholders and service providers to fully cater for their basic needs throughout the nation, especially in rural communities, where they are rarely seen. Unfortunately, due to the limited number of persons with albinism in Malawi, a major challenge for persons with albinism has been understanding their own condition. Other people such as teachers, their family and community members also find it difficult to understand albinism, making it difficult to provide for the necessary needs of persons with albinism.

The attacks, threats, killing, abduction, possession of body parts, and the exhumation of the graves of persons with albinism has left their family members traumatized upon seeing the dismembered bodies of their relatives. Furthermore, some of their family members have been attacked or hacked apart when the abductors invaded their homes to abduct or kill their relatives with albinism. This caused the affected families to voice their concern about the associated social problem as it required attention from both the government and relevant policy makers (United Nations, 2017). Studies about albinism have been conducted in Malawi by scholars such as Braathen and Ingstad (2006), Lynch et al (2014) and Schwering et al (2015). However, even though such studies have been conducted, not much is known about the social wellbeing and lived experiences of persons with albinism in Malawi due to the scant information available. Thus this study sought to contribute by filling in this particular research gap by exploring the lived experiences of persons with albinism in Lilongwe District, Malawi.

## **1.2 Objectives of the Study**

The main objective of the study is to investigate the lived experiences of persons with albinism in the Lilongwe District in Malawi. Specifically, the study seeks to achieve the following objectives:

- a) To identify the challenges faced by persons with albinism in Lilongwe District, Malawi.
- b) To find out the coping mechanisms of persons with albinism in Lilongwe District, Malawi.
- c) To ascertain the recommendations put forward by persons with albinism on how to improve their living status in Lilongwe District, Malawi.

## **1.3 Research Questions**

The following research questions guided the study in line with the objectives:

- a) What are the challenges faced by persons with albinism in Lilongwe District, Malawi?
- b) How do persons with albinism cope in Lilongwe District, Malawi?
- c) What are the suggested recommendations put forward by persons with albinism that can improve their living status in Lilongwe District, Malawi?

## **1.4 Significance of the Study**

Most of the research studies conducted on persons with albinism have focused on the health and education challenges they face, including societal beliefs and superstitions. Therefore this study's findings will provide a different perspective regarding the information available on the various challenges confronting persons with albinism and their coping mechanisms. The suggested recommendations will help the various stakeholders to find solutions that will effectively address the needs of persons with albinism in both the rural and urban areas of Malawi.

The findings of the study will contribute to bridging the lapses and gaps in the Malawi Disability Act that in turn exist in the policies relating to persons with albinism. The study will provide more information for the policy makers which could influence the design and implementation of the policies needed to empower persons with albinism. The study is important because it will also serve as a point of reference for further studies and stimulate national discourse on the support for persons with albinism in Malawi and the whole world. The study findings can help social workers in their work alongside other practitioners when providing aid to persons with albinism in order to allow them to better understand the challenges that they go through and their needs.

### **1.5 Definition of Terms**

**Pigmented persons:** Anyone without albinism

### **1.6 Organization of the Study**

This research is organized into five chapters. The first chapter is the introduction which describes the background, problem statements, objectives and research questions of the study. It also includes the significance of the study and the definition of the terms/concepts used. The second chapter presents a review of the relevant literature and several studies on albinism. The third chapter provides the research methodology that is comprised of the research design, the sources involved in the data collection, the data collection tools employed, the sampling technique, the sample size and the ethical considerations taken into account. The fourth chapter involves the data analysis, the data interpretation and the discussion of the findings. This is a very important part of the research because it provides the information needed to answer the research questions. Finally, the fifth chapter consists of the summary, conclusions and recommendations. This is another relevant chapter because the recommendations from the study will help to provide solutions to the phenomenon.

## CHAPTER 2

### LITERATURE REVIEW

#### 2.0 Introduction

This chapter presents a review of the literature on the lived experiences of persons with albinism. The chapter has been formulated in line with the objectives of the study. The topics covered in the literature review include a) the challenges faced by persons with albinism, b) the coping mechanisms of persons with albinism and c) the recommendations made by persons with albinism on ways to improve their lives.

#### 2.1 Challenges Faced by Persons with Albinism

Persons with albinism face challenges relating to both themselves and their social environment. These challenges can be found within themselves, in their families, in the community and society and through the cultural beliefs present. The challenges often include poor education, a lack of understanding of the knowledge available about albinism, economic problems, stigma and discrimination, in addition to health and emotional issues.

##### 2.1.1 Education Challenges

Persons with albinism find their society to be unfriendly towards them as most of the interventions do not favor them. Ndirangu's (2014) study conducted in Kenya revealed that the education institutions are not fully equipped to offer specialized education for persons with albinism. This agrees with the study conducted by Ndomondo (2015) that explored the challenges and opportunities related to educating students with albinism (SWA) in Tanzanian regular secondary schools. This revealed that the knowledge of the learning needs of students with albinism is still low among the body of teachers, school managers and educational supervisors. Therefore, the students with albinism who are generally visually impaired lack both support and adjustments such as extra teaching, optical devices, special text books,

adjusted examinations and other learning materials with enlarged prints that are necessary for persons with albinism to learn successfully. When the school authorities fail to be properly oriented on the condition and needs of persons with albinism, it becomes quite difficult to accommodate them. This contributes to the high dropout rate of pupils with albinism due to the negative attitude held by society.

The sidelining of persons with albinism begins early on in their lives. They are not always allowed to attend school (Baker, et. al., 2010). Persons with albinism are vulnerable and disadvantaged in different ways from the moment that they enroll in schools. Their striking differences in appearance that look ‘white’ in a black population can lead to physical abuse such as bullying and name-calling by the students as well as the teachers (Wan, 2003; Ndomondo, 2015). In a case study conducted by the University of Venda in South Africa, it was confirmed that other students would not sit near to the students with albinism in the classrooms. They avoided them at school events (Baker et al., 2010). In some instances, children with albinism are placed at the back of the class by pregnant teachers, as far away from them as possible (Metcalf, 2003). The pregnant teacher, upon being questioned about this, indicated that she feared that she will conceive a child with albinism if she looks at them. However, the child cannot see the blackboard, thus they fail to perform well in class (Ndomondo, 2015). In families where there may not be enough money to send every child to school, the parents may not opt to “waste” money on a child with albinism. This is a tendency that propagates the system of exclusion and leads to a high level of illiteracy among the persons with albinism (Allen, 2011). Kisanga & Jethro's, (2014) study investigated the impact of interventions in relation to the murder of persons with albinism in Lake Victoria, Tanzania. The study revealed that children with albinism no longer go to school alone. They do not go unless they are escorted by their father, mother or teachers as a result of the

abduction and killing of persons with albinism. Sometimes even the mothers are not allowed to walk outside for fear of the killers. This reduces the chance of persons with albinism succeeding in life, hence they have a more miserable existence.

### **2.1.2 Lack of Knowledge about Albinism**

A qualitative study by Braathen and Ingstad (2006) examined the knowledge and beliefs held in an African setting in Malawi using a sample size of 25 participants. The authors found that most people with albinism, as well as their families, have very little knowledge about albinism as a condition. However, many know that the skin of people with albinism is very sensitive to the sun. The authors further found that the participants lacked knowledge regarding what special aids people with albinism need in order to function well in their daily life. This resulted in a lack of protective clothing, sunscreen and visual aids which are collectively vital to their daily functioning. As a result, persons with albinism tend to fail to accept their condition as they have little knowledge of the biomedical explanation of it. This contributes to their marginalization by pigmented people (Cruz-Inigo, Ladizinski & Sethi, 2011; Ndiragu, 2014; Brocco, 2015; Marçon & Maia, 2019). Lund and Gaigher (2002) conducted a study on the health intervention programs available for children with albinism at a special school in South Africa. The results concluded that the lack of knowledge about albinism can lead to many superstitions such as albinism being the result of witchcraft. In addition, the study found similar myths that advocate that families with babies that have albinism are the victims of witchcraft.

### **2.1.3 Beliefs**

The traditional beliefs surrounding the birth of a person with albinism forces most parents to hide their children at home, fearing scorn from the community. The different beliefs and

myths related to persons with albinism tend to impact their wellbeing negatively. This results in their lives ending prematurely. According to Hong et al. (2006), the parents of children with albinism, especially the mothers, are subjected to many myths concerning the origin of albinism. The lack of education and accurate information on albinism leads the mothers to being ridiculed by society and their psycho-social wellbeing is negatively affected. Such ridicule includes being accused of sleeping with white men, with the conception taking place during menstruation which is regarded as culturally unacceptable and the child being a punishment from the gods for an ancestor's wrongdoing. Because of this, the quality of life of children with albinism may be compromised (Hong et al., 2006) as they are associated with the alleged immorality of their mothers and evil deeds. Witchdoctors in Tanzania have created a market for the body parts of persons with albinism, including their genitals. The myth is that PWAs are believed to be immortal and thus beneficial in rituals related to the mining of gold and diamonds (Mswela & Nöthling-Slabbert, 2013; Burke et al., 2014; Burke, Kaijage & John-Langba, 2014; Saffitz, 2018). People desperate for success in the form of good luck and money lead to a high rate of murder where the victims are persons with albinism that are principally killed for ritual purposes (Kisanga & Jethro, 2014). Such beliefs are fueled by poverty and a lack of education which leads to the occult market telling their clients to kill persons with albinism in order to become wealthy (Machoko, 2013). These beliefs force persons with albinism to hide out of fear of being killed and dismembered. In South Africa, persons with albinism are often perceived as a curse whilst in Zimbabwe, they are linked to water spirits, ascribed celibacy and evil spirits. Similar findings regarding the experiences of persons with albinism in Ghana and Kenya are available (Nkrumah, 2019, 2018; Nyamu, 2014). Bradbury-Jones et al (2018) investigated the beliefs, myths, traditions and attitudes that surround people with albinism in Uganda. The authors found that most Ugandans fear persons with albinism, viewing them with suspicion and believing that they

possess supernatural powers. The authors noted that PWAs in Uganda experience a lifetime of discrimination and alienation.

#### **2.1.4 Economic Challenges**

Persons with albinism are limited in their execution of economic activity as a result of their albinism condition, which is a disability. Disability can result in poverty due to the limited opportunities available for skills development and employment (Lorna, 2005). The job market for persons with albinism is limited, unlike the market for pigmented people. This is because they cannot work under the sun as their skin is delicate and it can easily get blisters. This can lead to skin cancer (Oliver, 2012). In order for them to effectively live a normal life, most of their income is spent on protective clothing and medical supplies. For instance, for pigmented people, other things may be a luxury but for persons with albinism, things like hats, sun screen lotion, spectacles, shoes, long sleeved clothes and monthly skin checkups at the hospital are necessary for their survival (Guy, 2006). Persons with albinism are disproportionately more affected by poverty than other groups of socially-disadvantaged persons due to their historical exclusion (Bines & Lei, 2011). This has manifested right from the foundation of the education system due to the lack of adequate educational provisions that are suitable for them. Social discrimination has forced most of them to drop out of school. Later on in life, persons with albinism face more difficulties when trying to secure employment that requires a good background in education. This is as they are less educated compared to the rest of the population (Hong et al., 2006). Persons with albinism struggle for social acceptance and their active participation in economic activities is a way of making ends meet.

### **2.1.5 Stigma and Discrimination**

Persons with albinism suffer stigma and discrimination in different forms because of their skin color and physical appearance, which contributes to their social exclusion. Brocco's (2016) study on albinism, stigma, subjectivity and the global-local discourses in Tanzania identified that stigma from the community was among the numerous challenging factors faced by PWAs. This includes strangers and those unfamiliar with persons with such a condition perceiving albinism as an abnormal condition. Besides health concerns, persons with albinism also have to cope with psychological and social challenges (Marçon & Maia, 2019). Most social discrimination stems from a lack of education about the causes of albinism coupled with a limited awareness of genetic inheritance. This gives rise to different misconceptions about albinism. Both their families and the persons with albinism are subjected to stigma and discrimination by their community as a result of the traditional myths surrounding the cause of albinism. This causes psychological distress (Marçon & Maia, 2019). As a result, many external factors affect their inclusion in the social, political and economic spheres. The latter statement is supported by Songwathana and Manderson (2001) and Link and Phelan (2001), who state that the unequal distribution of economic and political power arises because it is linked to the social hierarchies in society. With PWAs being a minority in society, it becomes difficult for them to be included due to discrimination and stigma. They are looked down on by those in a position of authority because of their physical appearance. Ndirangu (2014) adds that the challenges they experience tend to demoralize them both psychologically and economically. Lund et al. (2007) revealed that some people believe that if one shares items like utensils or if they have had any physical contact with persons with albinism, then he or she will develop the condition. This contributes to the isolation of persons with albinism in their homes and community gatherings. This

stigmatization from society affects the way that persons with albinism engage in any form of productive activity (Linda, 2012).

#### ***2.1.5.1 Terminology***

According to Hong et al's (2006) study in South Africa, it was confirmed that persons with albinism experience stigmatization from their fellow students, teachers and community. Their schoolmates give them many derogatory names. This is something that the authorities cannot control within the school setting (Ndirangu, 2014). Some families give names to their children with albinism as a way of expressing their feelings as a result of having a child with albinism. Such names may include expressions of bitterness, love, fear of the unknown or a need for vindication. In addition, communities use names that are derogatory in nature when referring to persons with albinism which affects their social interactions as it brings pain into their life. This creates social markings that are cemented by use of demeaning language in reference to persons with albinism. This is in order to subject them to stigma and discrimination (Okoro, 1975). Kagore & Lund, (1995); Lund (2005) revealed that the misconceptions and myths associated with teasing and name calling affects the level of self-esteem held by the persons with albinism.

#### ***2.1.6 Health Challenges***

Apart from the social, physical and economic challenges, persons with albinism experience health challenges due to a lack of proper health care systems that are available to meet the needs of their condition such as skin cancer screening and eye checkups. As most persons with albinism live in rural areas and are economically unstable, the distance barrier that needs to be overcome to access the major clinics and a lack of transport money contributes to their poor health status. Persons with albinism often delay seeking and receiving the medical

treatment that is vital for their health. Their skin is prone to skin cancer. Most of the time, persons with albinism seek treatment only when their skin problem is already advanced (Opara & Jiburum, 2010). Unfortunately, around 40% of persons with albinism with skin cancer do not conclude their treatment due to financial problems (Mabula et al., 2012) or they miss follow-up sessions because of their distance from the medical facilities ((Opara & Jiburum, 2010; Kiprono, Joseph, Naafs, & Chaula, 2012).

### **2.1.7 Emotional Issues**

Emotions are feelings brought about by an individual perception of an experience (Mutasa, 2013). According to Hong et al. (2006), persons with albinism experience emotional challenges because of the negative attitudes and stigma that cause fear within them, leading them to develop less assertive personalities than people without albinism. The authors further noted that persons with albinism tend to be more withdrawn from social situations in order to avoid being noticed due to psychological challenges. These findings are in relation to the studies conducted by (Braathen & Ingstad, 2006) and (Wan, 2003) who collectively found that persons with albinism often experience negative reactions, discrimination and stigmatization in their everyday life. Persons with albinism experience unpleasant emotions such as shame, bitterness and depression (Luthar & Blatt, 1993) which reinforces the feeling of low self-esteem.

#### **2.1.7.1 Fear**

The families of persons with albinism have been psychologically tortured and negatively affected by the murder of persons with albinism (Kisanga & Jethro, 2014). The killings done for the purpose of getting body parts have brought about more fear and insecurity for the persons with albinism (Masanja, Mvena & Kayunze, 2014). There is a predominant state of fear and a lack of security which makes the persons with albinism forced to stay indoors or to

turn to others to seek refuge in different places. According to Kisanga and Jethro (2014), children with albinism are no longer going to school alone. They are escorted by their father, mother or teachers. Sometimes even the mothers are not allowed to walk outside, fearing that the killers that may overpower them and abduct the child. This has created feelings of inadequacy, helplessness and hopelessness, leading to anger directed at themselves and emotional withdrawal which arises from frustration. This, in turn, results in depression (Brown & Mankowski, 1993).

#### ***2.1.7.2 Bitterness***

According to Mutasa's (2013) study on the psychosocial implications of oculocutaneous albinism in Manicaland in Zimbabwe, it was established that stigma and discrimination provoke emotions like anger and crying. In some cases, it leads to depression. Stigma and discrimination result in bitterness and low self-esteem which demeans the social identity of persons with albinism (Miller & Major, 2000).

#### ***2.1.7.3 Marriage breakup***

Persons with albinism experience psychosocial challenges in the context of the marriage institution where they find it complicated to establish steady marriage partnerships owing to the myths and misconceptions aggravated by a society that is not entirely ready to comprehend their condition. The condition for women with albinism is further compounded by gender dynamics (Mutasa, 2013). The lack of accurate information on albinism leads the mothers to being ridiculed and accused of sleeping with white men in society. Their psychosocial wellbeing is negatively affected. In a study conducted in Kenya by Ndirangu (2014) to investigate the strategies that persons with albinism can apply in order to sustain themselves economically, they found that men often leave after their wives give birth to a child with

albinism. They leave the burden entirely up to the mother when it comes to take caring of the child. At times, even the mothers take off, leaving the child/children with their grandparents (Ndirangu, 2014). Most single parents/grandparents have no means of income and they live a life that is hand to mouth (Anderson, 2006). The quality of life of children with albinism may be compromised (Hong et al., 2006). There are similar studies that confirm the above report. For instance, Gaigher, Lund and Makuya (2002) found that even choosing a marriage partner is a serious challenge especially for female persons with albinism, unlike it is for males with albinism.

## **2.2 Coping Mechanisms of Persons with Albinism**

Persons with albinism are stigmatized and marginalized in many areas of their lives such as intimate relationships, employment and access to public areas (Wan, 2003). Due to society's exclusionary measures, they have developed coping mechanisms in order to manage the adversities that they are faced with by joining and forming support groups like religious congregations and/or community-based organizations (Wan, 2003). Persons with albinism, their families and society also manage to develop resilient strategies in order to overcome the misfortune that they face daily.

Pooe-Monyemore, Mavundla and Christianson's (2012) findings on the experiences of persons with albinism in Johannesburg, South Africa, revealed that persons with albinism felt that they 'themselves' can eradicate the myths and superstitions associated with albinism and thus maintain their self-worth. This was done by utilizing the counseling information and knowledge received from the albinism association in order to maintain a positive attitude by accepting themselves and conducting awareness programs on albinism. These problems are shown to their communities rather than hiding themselves from the public. In addition, the PWAs in this study felt that unity among themselves in order to educate their communities

could help to eradicate the myths that are associated with them. Persons with albinism also aim to show the world that they deserve to be treated with dignity through their interactions with the external environment. This has influenced their self-image and fostered a sense of belonging at home and in the community. Social support groups such as religious congregations and community-based organizations also contribute to the formation and transformation of the subjectivities of persons with albinism regarding the creation of a group identity within their communities and society (Brocco, 2016).

Persons with albinism are frequently disadvantaged across Africa, although community outreach programs try to provide support for them and their families (Hong et al., 2006). They provide the necessary information regarding albinism. Professionals, politicians and musicians in the higher socioeconomic strata have used their public status to support the cause of persons with albinism in order to improve the health care systems that appear to lack a certain responsiveness to the needs of persons with albinism (Hong et al., 2006).

Fayoyin and Ihebuzor (2014) examined the advocacy tools used for advancing the rights of albinos in Tanzania and Osus in Nigeria. The case study approach was utilized using secondary data analysis as the main source of information. The study found that advocacy plays a major role in influencing both public and policy outcomes for persons with albinism. Additionally, the advocacy suitably positioned in the national and international agenda and the involvement of key religious leaders who have spoken against the negative practices focused towards persons with albinism have both helped some of the traditional chiefs to abolish harmful practices in their communities. The authors found that in Tanzania, among the formal support available was a pronouncement from the President in support of persons with albinism. This will lead to more arrests and the increased prosecution of the violators of

the human rights of albinos. To add to this, the position in the national and international agenda of albinism brings in more support for persons with albinism worldwide (Fayoyin & Ihebuzor, 2014).

Persons with albinism are generally reported to be of a lower, if not the lowest, economic status in their society. Awareness groups and public health interventions help to support them when it comes to meeting and coping with their medical and psychosocial needs (Cruz-Inigo, Ladizinski & Sethi, 2011). Persons with albinism who have visual impairments are enrolled in specialized schools for the blind (Hong et al., 2006) where they learn Braille and other skills. In addition, Schwering et al (2015) indicated that all identified persons with albinism in Malawi were given a free pair of learner visual devices (LVDs) and spectacles. The authors noted that a file containing recommendations for the parents and teachers of children with low vision was handed over to the respective school head-teachers for safe-keeping (Schwering et al., 2015).

Furthermore, Ndirangu (2014) indicated that formal support in the form of rehabilitation, enhanced self-determination and independence in persons with albinism provides good avenues of awareness through which the PWAs are motivated and empowered. Improved security helps the persons with albinism to cope and live a peaceful life like everyone else (Cruz-Inigo et al., 2011). Due to the cultural and traditional myths regarding albinism, persons with albinism have to cope with being hunted for their body parts and they suffer both emotional and physical trauma (Cruz-Inigo et al., 2011) that is detrimental to their wellbeing.

### **2.3 Recommended Ways of Improving the Lives of Persons with Albinism**

When persons with albinism understand their rights and needs, they are able to provide better solutions to the challenges that they encounter. Poor eyesight is a major challenge that persons with albinism experience from infancy. Lynch, Lund and Massah (2014) and Schwering et al (2015) found that the provision of early eye screening for children with albinism improves and corrects their visual sensitivity. This helps them to avoid the progression of amblyopia (lazy eyes).

According to Ndirangu (2014), providing PWAs with equal opportunities in terms of employment, relevant training and rehabilitation programs as well as sensitizing the various organizations present in the context to the need to support PWAs in their decision-making processes enables them to feel accepted in their society and environment. In support of the above, Braathen and Ingstad (2006) revealed that persons with albinism understand that they can contribute to society alongside people born with pigment. However, there is still the need for inclusion in the decision-making process to fight for their basic human rights.

In addition to the above, Linda (2012) found that persons with albinism are empowered when people and organizations offer resources that enable them to feel accepted and able to participate in the building of society. This allows persons with albinism to engage in productive activities. Awareness programs that target persons with albinism living in rural areas may bring about an increased level of knowledge about albinism which could help in the management of their condition and extend their lifespan. The studies conducted by Poee-Monyemore, Mavundla and Christianson (2012) and Kromberg and Braathen (2006) found that clinical genetic outreach programs in rural areas assisted the parents in the management of the condition of albinism through understanding and acceptance, thus removing ignorance and superstitions.

## **2.4 Theoretical Perspective**

### **Resiliency Theory**

Resilience is defined as the ability to bounce back from adversity, frustration and misfortune (Ledesma, 2014). Kumpfer (1999) grouped resilience into six major parts and they incorporated both process and outcome views. The six major parts are 1) the presence of stressors or challenges, 2) the external environmental context, 3) the person-environment interactional process, 4) internal self-characteristics, 5) resilience processes and 6) positive outcomes.

Stressors or challenges activate the resilience process and they create disequilibrium or a disruption in the homeostasis of the individual or organizational unit (e.g. family, group, community). The degree of stress perceived by the individual depends on their perception, cognitive appraisal and the interpretation of the stressor as either threatening or aversive. Persons with albinism may also experience challenges from individuals, families, the community and culture itself which could hinder their wellbeing.

The external environmental context includes the balance and interaction of the noticeable risks, protective factors and processes present in the individual's external environment in critical areas of influence (i.e. family, community, culture, school and peer group). These interactions change with age and they are specific to the culture, geographic location and historical period. Persons with albinism may fail to cope with the challenges encountered as a result of a lack of support. For instance, if at a younger age both the individual and the external environment fail to understand albinism, then demeaning names, stigma, discrimination and rejection are developed towards the persons with albinism.

Person-environment interactional processes include the transactional processes between the person and his or her environment. It also includes the care that others either passively or actively attempt to perceive, how they interpret and surmount threats, and the challenges in the environment encountered while trying to construct more protective environments. Likewise, persons with albinism are in a position to overcome challenges and difficult environments by adopting protective measures such as avoiding the sun, going for regular skin checkups, seeking counseling and information on albinism, forming their own clubs and by strengthening protective factors such as wearing protective clothing and applying sunscreen lotion.

Internal self-characteristics include an individual's spiritual, cognitive, social/behavioral, physical and emotional/affective competencies and strengths. These are collectively needed to be successful in different developmental tasks, cultures and personal environments. Persons with albinism have the strength and desire to cope with the challenges around them from different corners, if they are given support at all. For example, seeking counseling for emotional support and attending church for spiritual support where they can engage in different activities are both great avenues. Socially, persons with albinism get support from other individuals with albinism as well as from NGOs.

Resilience processes include unique short-term or long-term resilience and the coping processes learned by the individual through gradual exposure to the increasing changes and stressors that help him or her to bounce back through resilient reintegration (Richardson et al, 1990). Persons with albinism develop their own measures to cope with their condition. This sometimes may depend on the intensity of the challenges that they are exposed to. For instance, some may opt to accept their albinism condition, which is long term, whereas others may opt to withdraw from social activities for the short term until they are healed.

Positive outcomes or successful life adaptations concerning specific developmental tasks are supportive of later positive adaptations related to specific new developmental tasks culminating in a higher likelihood of reaching the global designation in adulthood of being a "resilient child or adult." This is, in a dynamic model, a positive outcome suggesting that resilience is also predictive of later resilient reintegration after a disruption or stress. Persons with albinism who bounce back from challenges are able to become resilient. Some can become successful in their academic careers, going on to advocate and advise their colleagues about albinism, thus becoming role models to those with the same condition. This promotes positive living.

These six areas help to clarify the differences between environmental stimuli, transactional environment buffering processes, internal mediating self-factors and the resilience processes that are used to bounce-back after a challenge in addition to the final developmental outcomes of resilient persons with albinism.

### **2.5 Usefulness of Resilience Theory**

The theory of resilience helped the researcher to understand how the risk factors such as poor eye sight, demeaning names and a lack of knowledge hindered the persons with albinism from bouncing back from situations such as dropping out of school. The theory was useful for identifying some of the factors that supported the persons with albinism when they were coping with their albinism including counseling, personal development, security, networking, acceptance of their albinism and support from their family and friends.

## CHAPTER 3

### RESEARCH METHODOLOGY

#### 3.0 Introduction

This chapter discusses the methods that were used when undertaking this study. The chapter is comprised of the research design, target population, study population, sampling technique and sample size. The methods employed in the data collection and the steps through which the data was analyzed and interpreted are explained and lastly, the ways in which trustworthiness was ensured are also described in this chapter.

#### 3.1 Research Design

Social research needs a design or a structure before the data collection and subsequent analysis can commence. A qualitative research method was used for this study by the researcher to record the untold stories of what happens, how it happens, why it happens and the way that it happens (Henning, 2004) in the context of the lives of persons with albinism. According to McMillan, James and Schumacher (2010), qualitative research is concerned with the processes and meanings that will enable the researcher to gain richer and in-depth information on the experiences of the participants. Using a qualitative research design enabled the researcher to understand the lived experiences of persons with albinism (McMillan, James & Schumacher, 2010), in addition to identifying their challenges, the coping strategies they adopted and their own recommendations to improve their lives. Polit and Beck (2010) maintained that qualitative research gives the researcher the opportunity to conduct a study in an in-depth holistic manner by collecting rich narratives while using an unrigged research design.

An interpretative phenomenological approach in this qualitative research study was specifically used. According to Smith and Eatough (2006), the interpretative

phenomenological approach focuses on making sense of human experiences and actions. It is concerned with the detailed examination of individual lived experiences and how individuals make sense of those experiences (Eatough & Smith, 2007). This approach, as it explores the personal experiences of persons with albinism, is concerned with an individual's perception or account of an object or event (Smith & Osborn, 2008). Furthermore, an interpretative phenomenological study usually involves a small number of participants in order to understand how and why things happen and how people relate to the phenomenon (Smith & Osborn, 2008).

### **3.2 Study Area and Site**

Lilongwe District, which is in the Central Region and Capital city of Malawi, was chosen as the study area. According to the Malawi Population and Housing census (2019), Lilongwe District has an estimated population of 2,626,901 of which 1,637,583 people reside in the rural areas and 989,318 people reside in the urban areas. The district was selected because of the location of the Association for People with Albinism's (APAM) offices where the recruitment and identification of persons with albinism and related key informants was made easy. The organization is involved in activities that are geared towards addressing issues related to PWAs and it was thus able to provide useful information on albinism.

APAM is a non-governmental organization that was established in 1995 that focuses on advocacy for persons with albinism. Their mission is to improve the status of persons with albinism in Malawi by advocating for fair treatment, respect and dignity in a manner that is consistent with the Universal Declaration of Human Rights and its Convention on the Rights of Persons with Disabilities (World Albinism Alliance, 2015). APAM supports over 2,500 persons with albinism across Malawi which totals about 25% of the population (Holsteijn, 2016) in different catchment areas. Persons with and without albinism work for APAM. The

association is partnered with several organizations such as Sight Savers and Under the Same Sun which provide funding for specific activities and projects.

The main functions of the association are to provide information and consulting services to the public authorities about albinism, to ensure that persons with albinism are taken into consideration when policies and legislation are formulated and to act as an advisory body for the authorities on matters related to persons with albinism in Malawi. In addition, APAM provides individual counseling on skin protection and it seeks to raise the level of community awareness on the issues surrounding albinism through public talks, the media and research studies (Lynch, Lund & Massah, 2014).

### **3.3 Study Population**

Population refers to any set or group of persons or objects that possess at least one common characteristic (Badu-Nyarko, 2011). For this research, both the population of persons with albinism and the key informants serving as the representatives of the three organizations involved namely APAM, Kanengo in the Protection of Rights of People with Albinism (KAPRA) and Musical Crossroads – Malawi (MCM) from Lilongwe District took part in this study. The APAM participants were from Lilongwe’s rural areas whilst those from MCM and KAPRA were from Lilongwe’s urban areas in Malawi. Both of these groups were purposively sampled to participate in this study.

Kanengo in the Protection of the Rights of People with Albinism (KAPRA) is a registered non-profit Non-Governmental Organization (NGO) operating out of Kanengo Police Station with the aim of sensitizing the surrounding communities to the condition of albinism. The organization is operated by persons without albinism of which some of them are police officers in the Victim Support Unit at Kanengo Police Station. Currently, the organization

does not have any sources of funding. The main functions of the organization are to collect the data of persons with albinism in their catchment areas, to safeguard the lives of new babies born with albinism by giving proper guidance and counseling on the care of children in the form of organized awareness, to educate the community about albinism and to provide support and skills to the community police force. KAPRA encourages the beneficiary to register with APAM as the mother body of PWAs to enable them to be considered for any other programs. They will also benefit from the donations that APAM receive from other donors.

Music Crossroads - Malawi (MCM) is a registered non-profit Non-Governmental Organization (NGO) that was established in 2007. It aims to empower youths through music, an initiative that began in 1995 led by Jeunesses Musicales International (JMI) with Music Crossroads International. The training centre in Lilongwe promotes musical creation and performance as well as life skills training. The program also targets persons with albinism in order to encourage them to engage in skills training through the sponsorships and funding from the European Union. The training that focuses on employability skills utilizes the models known as Contributing Positively to Society (COPOSOS) and Supporting Employability and Personal Effectiveness (SEPE). These programs are operational in the Netherlands, South Africa and Colombia. The participants go through a 12-week training program through which they acquire a life skill, after which they are awarded with a COPOSOS certificate. Those under SEPE are awarded with an internationally-recognized SEPE certificate issued by Pearson Education, an international company focused (among other things) on the development of training and educational programs.

### **3.4 Sampling Technique**

Persons with albinism aged between 18 to 62 years were recruited in this study. The researcher envisaged that within this age bracket, the participants would have more to tell on their lived experiences. The inclusion criteria also included those who understood the Chichewa and English languages. Those who did not understand either Chichewa or the English language were excluded because the researcher could not get an interpreter for the other local languages. The key informants from APAM, MCM and KAPRA who had worked with persons with albinism for at least a year were recruited because they would have gained more experience related to the lives of persons with albinism.

Purposive sampling technique was used in this study. Purposive sampling was appropriate because it helped the researcher to select the sample size based on their prior knowledge, the nature of the research objectives and according to the criteria determined by the researcher's purpose (Babbie, 2013; Tuckett, 2005). It was also selected with the purpose of representing a location or a tie to a key criterion (LeCompte, Preissle & Tesch, 1993). Using a purposive sampling design helped the researcher to use her discretion for the selection of samples from the study population. Purposive sampling was appropriate because the researcher studied a small subset of the population of PWAs (Babbie & Babbie, 2007).

### **3.5 Sample Size**

Thirty participants were sampled by the researcher consisting of fifteen females and fifteen males who met the criteria required by the researcher. Out of that number, twenty-seven participants were persons with albinism. Three persons without albinism were selected as the key informants from APAM, KAPRA and MCM in Lilongwe District. The final sample size was chosen because a qualitative study does not aim to generalize and the researcher reached saturation with the given numbers. Data saturation, according to Fusch and Ness (2015), is

reached when there is enough information to replicate the study once the ability to obtain additional new information has been attained and when further coding is no longer feasible. Furthermore, a large sample size could lead to repetitive data from the participants (Crouch & McKenzie, 2006; Mason, 2010).

### 3.6 Sources of Data

The primary data was collected through qualitative in-depth face to face interviews and focus group discussions in both the rural and urban areas of Lilongwe District. The in-depth interviews helped in the collection of the information grounded in the lived experiences of the research participants (Creswell, 2008). It also provided the participants with the chance to express their subjective views about the issues that were discussed.

The data production used in the study included three focus group discussions (FGD), individual interviews and key informant interviews.

<b>Method Used</b>	<b>Number of Participants Engaged</b>	<b>Female</b>	<b>Male</b>
FGD 1- men only (APAM)	8	0	8
FGD 2 - female only (APAM)	6	6	0
FGD 3 - Mixed (male and female) (KAPRA)	6	3	3
Individual interviews with the PWAs ( 3 MCM and 4 APAM)	7	4	3
Individual interviews with the key informants (APM, KAPRA and MCM)	3	2	1
<b>Total</b>	<b>30</b>	<b>15</b>	<b>15</b>

*Table 1: Data source*

The researcher conducted two separate focus group discussions with eight males and six females from the remote areas of Lilongwe's rural district. The participants were from the APAM catchment area. One mixed focus group discussion comprised of three men and three women was conducted at the KAPRA offices in Lilongwe's urban district. In addition, three interviews were conducted with the participants from the MCM offices whilst the three individual interviews with the APAM members were conducted in their respective homes. One individual interview was held in a separate village in the rural area of Lilongwe District with a member of APAM and they were not part of the focus group discussions. Furthermore, individual interviews were conducted with the three key informants who were working with persons with albinism selected from APAM, KAPRA and MCM.

### **3.7 Data Collection Methods**

#### **3.7.1 Pre – Data Collection**

The initial informal conversations with the Program Manager of APAM and two persons with albinism were conducted in July 2017 in Lilongwe District, Malawi. Since the study was conducted in Malawi, it was a requirement of the National Commission for Science and Technology (The National Board for Research and Ethics Committee) to obtain clearance and approval from the Ethics Committee for the Humanities (ECH) of the University of Ghana. The approved ethical clearance from University of Ghana was submitted together with the other required documents to the National Commission for Science and Technology and the Ethics Committee for the Social Sciences and Humanities in Malawi for their final approval in order for the researcher to conduct their study in Malawi on persons with albinism.

### **3.7.2 Observation**

The researcher paid a visit to the skin clinic assigned to the PWAs in order to observe how they came to the clinic and how they were received at the clinic. A few weeks before the interviews began, the researcher spent a handful of days volunteering and collecting HIV/AIDS data for the PWAs on behalf of the Catholic Relief Service with an APAM member. This helped the researcher to familiarize herself with persons with albinism and some of the participants. A day was spent with the family of one participant to observe the way that he spent the day together with the rest of his clan members.

### **3.7.3 Data Collection Procedure**

The researcher was granted approval to conduct research by the Ethics Committee for Humanities (ECH) of the University of Ghana, the National Commission for Science and Technology and the Ethics Committee for the Social Sciences and Humanities in Malawi. The researcher went to the APAM offices with the ethics approval letters together with a letter of introduction from the Department of Social Work of the University of Ghana to propose conducting interviews with the members of APAM. APAM granted the researcher access to interview its members with albinism. APAM appointed one of its members, a person with albinism, in order to assist the researcher with the identification of suitable locations and a sensible recruitment process. The APAM member acted as a research assistant who helped the researcher to schedule the necessary meetings. The participants were recruited from the APAM catchment areas in both the rural and urban parts of Lilongwe District, in addition to the MCM and KAPRA offices respectively. Approval to conduct meetings with PWAs in Lilongwe's rural district was sought through a member of APAM who informed the chiefs and the APAM committee leaders of the intended purpose of the meetings a few days before the initial meeting itself. This was necessary because it was a

sensitive matter to be associated with persons with albinism during the time when the study was being conducted. This is as there were many cases of PWA abduction and killing in Malawi. The families and community members were, as a result, very suspicious of any strangers in their communities who wanted to get in touch with PWAs. Furthermore, it was important for the researcher to win the trust of the participants especially after consulting with the leaders in their respective catchment areas. It helped the families to allow their relatives with albinism to participate in the study as they felt secure because their community leaders and families were aware of the meetings. The APAM office contacted MCM and KAPRA concerning the intended study on behalf of the researcher. With the help of the research assistant, appointments were booked to meet the participants from the APAM catchment areas, in addition to those of MCM and KAPRA. The twenty-seven participants in the study were recruited on the basis of having albinism whilst the three key informants were officials from APAM, MCM and KAPRA working with persons with albinism. This technique eliminated bias and gave every individual the same probability of selection.

In all of the interviews and focus group discussions, the purpose of the study was explained to the participants before they willingly gave information. The researcher clearly articulated to the participants that there was no material or monetary gain to be gained by being involved in the research. However, the findings could still be used for policy guidance and advocacy work in the various communities. The participants who were not comfortable discussing the issues related to albinism were excused from the research and those who participated agreed to a statement of consent in order to confirm their understanding of the study as well as their readiness to participate. The participants were not forced or coerced to partake in the research. They did so of their own free will. The rights of participants were respected. They were provided with an explanation of the research and they were told that they were at liberty

to terminate their participation if they did not feel comfortable, even though they had been encouraged to participate. The participants then signed or thumb-printed a consent form as evidence that they had made an informed decision to participate in the research. With the permission of the participants, a voice recorder was used to record the oral interviews which complemented the field notes.

#### **3.7.4 Instruments for the data collection**

Two interview guides were designed for the persons with albinism and for the key informants respectively in both English and Chichewa (the local language). However, the interviews were conducted only in Chichewa based on the participants' choice. The instruments were used to solicit information from the participants through focus group discussions and individual interviews. Two different interview guides for the participants and key informants were used to ensure consistency in both the content and context while remaining conversational and free to probe into unanticipated circumstances and responses (Babbie, 2013). The questions for the interviews were designed based on the literature review and resilience theory.

#### **3.7.5 Focus Group Discussions**

The researcher conducted three separate focus group discussions (FGDs) comprised of eight males and six females from the Lilongwe District rural area on 11<sup>th</sup> January 2018. One mixed gender focus group discussion comprised of three males and three females was conducted on 16<sup>th</sup> January 2018 at KAPRA Conference Hall in Lilongwe District Urban area. This was necessary because it was felt to be a conducive environment in which to conduct the discussions with persons with albinism. The focus group discussions lasted between two hours and two hours thirty minutes. This was because the participants spent the first fifteen minutes opening up. The participants in the mixed FGDs all resided in the city of Lilongwe.

The men and women in the rural areas were separated during the discussions to enable the participants to express themselves freely. This was because their culture does not allow women to talk much during special gatherings with men. The researcher wanted to hear about the lived experiences concerning gender. The mixed FGDs were used to find out if some of the experiences and challenges faced were the same for both males and females. The participants from the mixed FGDs were from different cultural backgrounds.

The focus group discussions were conducted with six to eight participants and the researcher introduced herself and welcomed the participants. The participants also introduced themselves and the aim of the focus group discussion was explained to the participants. Ground rules were established where each participant had to mention his or her name before answering the question and they had to give room for others to express themselves freely. Any concerns and fears from the participants were checked and resolved. The questions were asked by the researcher according to the interview guide. Before the end of each gathering, the researcher thanked the group members for their participation, stressed how helpful the discussion had been and reassured them of their privacy.

According to Casey and Krueger (2000), Krueger's method of (2000) focus group discussions should incorporate six to eight participants. Focus group discussions are seen of as appropriate research methods as they allow the participants to feel a sense of collective identity and solidarity (Kitzinger, 1994). Additionally, focus groups discussions often have the potential to stimulate the participants' memories because the members of the group learn from each other, and exchange and build on each other's views. This, in a way, can make the participants experience the research as an enriching encounter. Focus group discussions are helpful when one is researching difficult participants who are marginalized or stigmatized, or

who feel unsafe (Kitzinger, 1994) such as persons with albinism. Therefore, the focus group discussions minimized the sense of insecurity that the participants with albinism could have experienced and they made them feel safer, comfortable and more relaxed in a group research study.

### **3.7.6 Individual Interviews**

Four individual interviews were conducted at the participants' homes with their permission on 18<sup>th</sup> and 19<sup>th</sup> January 2018. Three individual interviews were conducted at the MCM offices on 24<sup>th</sup> January 2018. Some of the interviews took longer because the participants took longer to open up in the in-depth interviews as they were shy. The interviews lasted between forty minutes and one hour.

### **3.7.7 Key Informant Interviews**

An interview guide was utilized to collect the necessary data from the key informants. Three key informants were identified. The interviews with the key informants were conducted in their work places, namely the KAPRA, MCM and APAM offices. The interviews sought to establish what the key informants knew about the experiences of persons with albinism as they worked with them. The researcher also wanted to know the support that was being given by the government and donors to PWAs.

### **3.7.8 Data Handling and Analysis**

Qualitative data was collected from the focus group discussions, individual interviews and key informant interviews. The data was transcribed and where necessary, translated into English. To analyze the data, the researcher used interpretative phenomenological analysis. An interpretative phenomenological-based approach was appropriate for the study as it

intended to bring to the forefront the everyday experiences of the sample group as presented during the interview. The researcher adopted Van Manen's (1990) six steps of phenomenological analysis. The following are Van Manen's six steps of phenomenological analysis that were followed.

The researcher repeatedly read the participants' descriptions until the researcher was familiar with what had been said. The second step was re-reading the data in order to identify and highlight meaningful phrases, statements or words that seemed to be important concerning the phenomena being studied. Each significant statement was noted. Different statements were organized into clusters of themes. Common or similar themes in terms of meaning were identified and grouped together. The researcher tried to find links between the themes and then described and summarized them. Regularities and sets of similar ideas were grouped into sub-themes and then compared (Van Manen, 1990).

### **3.7.9 Credibility and trustworthiness**

To ensure the credibility of the study, experts who were not part of this study provided their input through a peer debriefing. The findings of this research were presented to the members of the faculty of the Department of Social Work who are knowledgeable in qualitative research. The faculty members had the opportunity to query the research methods that were adopted for the study, in addition to the meaning and interpretation of the data. Colleagues and supervisors were consulted and their input was taken into account. In order to ensure that the study was trustworthy and credible, the researcher had to find out if the responses were in line with their thoughts during the interviews. The participants were asked repeatedly to verify the accuracy of whatever had been said or noted in order to help reduce bias.

### **3.7.10 Limitations of the Study**

The present study was conducted only in Lilongwe District with a small population size. The findings of the study may not be generalized. The study might be restricted because the researcher selected her participants purposively and used a qualitative research design. However, the study still provides significant information on the lived experiences of persons with albinism in Lilongwe District which could be useful concerning the different stakeholders.

There are possibilities that data has been lost through the translation of the original responses from Chichewa (local language) into English. However, the researcher used the closest corresponding words that depict the ideas of the participants. To address this challenge, a second translator was employed to play back the audio-recorded data in order to verify the authenticity of the transcribed data. The study was conducted at the time when there were a lot of abductions, killings and body part harvesting targeting persons with albinism. To safeguard the lives of the persons with albinism, the location of the rural area where the study was conducted has not been mentioned in the study.

### **3.7.11 Ethical Considerations**

Ethics are the rules that suggest the expectations about the most correct conduct towards any experimental subjects (Vadum & Rankin, 1998). To ensure that the researcher will operate within the expected research ethics limits, the following research ethical standards as stipulated by the American Psychological Association in 1983 were adhered to. Clearance and approval to conduct the research was sought from the Ethics Committee for Humanities (ECH) - ISSER, University of Ghana, Legon, the National Commission for Science and Technology and the Ethics Committee for the Social Science and Humanities in Malawi. The participants' right to self-determination was respected.

When reporting the findings, pseudonyms were used in place of the actual names of the research participants. This was to ensure that the participants' identity was not revealed. The researcher ensured that the participants were protected from physical and mental discomfort, harm and danger. Because the study was about sensitive emotional issues, prior arrangements with a registered counselor were made in case any of the participants experienced mental discomfort. The researcher was as open as possible with the participants. Plagiarism was avoided by acknowledging all referenced sources.

### **3.7.12 Dissemination of the Findings**

The researcher's goal is to first share the study findings with the participants in their different locations within Lilongwe's rural district and Lilongwe's urban district. The researcher will also share the findings with the NGOs working with persons with albinism. The findings could help the relevant stakeholders to review their activities and to plan their interventions in line with the recommendations and needs of persons with albinism. Copies will be shared to APAM, KAPRA, and MCM, the Malawi Ethics body and the Ministry of Gender and Disability. Furthermore, the researcher will publish the study in human rights and albinism academic journals to enable scholars to fill in any suitable research gaps in the future. The study will also be made available for use in academia.

## CHAPTER 4

### PRESENTATION OF THE FINDINGS AND DISCUSSION

#### 4.0 Introduction

This chapter covers the findings of the study as well as the discussion of the findings. The findings are presented in terms of the demographic characteristics of the PWA participants and their lived experiences, including the challenges that they encounter as a result of their condition, their adopted coping mechanisms and the suggested recommendations that could make their lives worthwhile and productive.

The demographic data of the participants shows their personal characteristics and the employment of the study population. It also predicts the quality of the data obtained for the analysis (Barro & Lee, 2013). For this purpose, their age, marital status, ethnicity, educational background and occupation status were assessed.

#### 4.1 Demographic Information of the Participants

<b>Age Range</b>	<b>18 - 62 years</b>					
<b>Marital Status</b>	<b>(17) Married</b>	<b>(3) Divorced</b>		<b>(2) Separated</b>		<b>(5) Single</b>
<b>Ethnicity</b>	<b>(21) Chewa</b>	<b>(3) Tumbuka</b>		<b>(2) Chawa</b>		<b>(1) Ngoni</b>
<b>Educational Background</b>	<b>(4) No schooling</b>	<b>(9) Lower Primary School</b>	<b>(3) Upper Primary School</b>	<b>(2) Junior Cert.</b>	<b>(7) MSCE</b>	<b>(2) University</b>
<b>Employment Status</b>	<b>(15) Unemployed</b>	<b>(4) Casual worker</b>		<b>(4) Student</b>		<b>(1) Messenger</b>
						<b>(1) Admin</b>
						<b>(1) Nurse</b>

*Table 2: Demographic characteristics of the participants*

The study selected 30 participants in total (15 males and 15 females). The final number is comprised of twenty-seven persons with albinism and three key informants from Lilongwe District. The participants for this study consisted of persons with albinism between the ages of 18 and 62 years, comprised of women between the ages of 20 and 62 years. The men were aged between 18 and 40 years.

Regarding the marital status of the persons with albinism, seventeen out of the twenty-two participants were married. Three women were married to pigmented men, eight men were married to pigmented women and the remaining six were married to fellow persons with albinism. In addition, three women who were once married to pigmented men were divorced and none of the male participants were divorced. Two of the women who were separated were once married to pigmented men whereas none of the men had been separated. Five of the participants were single, including one female and four males.

Regarding ethnicity, the study findings noted that twenty-one out of the twenty-seven participants were of the Chewa tribe normally found in the Central region of Malawi. Three participants were Tumbukas and one Ngoni, both from the Northern region. Two participants were of the Chawa tribe, mostly found in the Southern region of Malawi. However, all of the participants lived in Lilongwe District.

In terms of their education background, four out of the twenty-seven participants did not attend school and nine had completed their lower primary education (standard one to four). Three participants reached upper primary level (standard five to eight). Sixteen participants who had no formal education, either lower primary or upper primary, and they were from the remote rural areas. Two of the participants managed to reach junior secondary level and

obtained a Junior Certificate (JCE). Seven participants reached senior secondary level but they did not do well in their Malawi School Examination Council (MSCE) exams. One participant had a Junior Certificate (JCE) and three who had passed their MSCEs were undergoing tertiary courses in tailoring and music. Two of the participants had university degree qualifications in Business Administration and Nursing respectively.

Out of the twenty-seven participants, eight had various occupations that were their source of income. These included four who were doing casual work in the community, included cultivating other people's farms. Two of the participants were working as office messengers, while one was an administrator and one was a nurse. Four of the participants were students while fifteen of the participants had no occupation, hence no source of income.

#### **4.2 The Challenges Faced by Persons with Albinism**

The following themes emerged for the challenges experienced by persons with albinism namely barriers to education, attitude, a lack of knowledge about albinism, economic restraints, stigma and discrimination, health care and emotional issues. These challenges affect persons with albinism socially, emotionally and physically.

##### **4.2.1 Education Challenges**

Persons with albinism recalled the challenges that they experienced in terms of their education as young children. The challenges in education started from a young age, namely the moment that the PWAs enrolled, especially when their peers tried to make sense of the difference in their skin color and eye movements. The PWAs inability to see the blackboard well whilst all their peers were able to see without any challenges made the PWAs realize that they had problems with their eyes. In most cases, the PWAs did not get support from the teachers in their class because the teachers in those days did not understand albinism and how to handle PWAs in class. This is because it was not taught about in schools. They gave an

account of how they felt and how they struggled with their academic journey. The participants noted that the font size in the text books that were used in class was too small for them to read. The reading difficulties were also experienced as a result of their wobbling eyes which, according to them, made the letters in the books not stable. Sadly, the abduction of persons with albinism from schools started to make them to drop out of school. This is as they were afraid of being abducted and killed for ritual purposes. In their responses, they attested the following:

When I was in school, I faced a lot of challenges because I could not see well, even when the book was very close to me. My eyes gave me tough times (Joy - Individual Interview, male - MCM).

I have severe eye problem that worry me even up to now. Because of my eye problem, I failed to progress in my school. Everything was difficult to me. The letters in the books were not stable and it was difficult to read them well (Rachel- FGD2, female, LL rural).

Some of the participants experienced challenges when reading because it was difficult for them to see the blackboard despite sitting in the front row seats. This affected them in terms of their performance in school:

I failed to do well in school due to the obstacles that I faced during my school days. I could not see well what was written on the blackboard when all of my friends in class did not have any problem. That is the reason why I could not continue with my studies (Daniel - FDG1, male, LL rural).

My grades were always bad in school... I was finding it difficult with my eyes to see the figures well on the blackboard in the class (Saul - FGD3, male, KAPRA – LL urban).

Some of the participants expressed that they had to stop going to school because persons with albinism were being abducted when going to or coming back from school by people in the

macabre business of body part harvesting, specifically the body parts of PWAs. He narrated that:

The news was all over that persons with albinism were being abducted and killed on their way to or from school. Me and my family were terrified and afraid. Immediately I stopped going to school due to the killings that are still taking place (James - FGD3, Male, KAPRA- LL urban).

#### **4.2.2 Attitudes**

The participants also expressed how they were treated by their peers, teachers, family and society. It was noted from the study that most of the participants dropped out of school at primary school level because of visual challenges. Nonetheless, two of the other factors that contributed to them dropping out of school included the attitude of their teachers and bullying by their peers, who were fond of pinching them while the teachers did not do anything about it. This was evident in the participants' narrations:

I stopped going to school when I was in class 3 because I had a very bad female teacher who used to call me names throughout the class session ... (Rose- FGD2, female, LL rural)

In our days, when a teacher was asking a question during [the] class session, he will not pick a PWA to answer the question despite the PWA knowing the answer. Instead the teacher will nominate a pigmented child. Worse still, if a person with albinism asks a question, then the teacher will ignore them and not answer (Solomon - FGD1, male, LL rural).

When I was in school in lower primary, my peers thought that I did not have blood and they would come and pinch me to see if the blood would ooze from my skin (Sandra - FGD3, female, KAPRA, LL Urban).

One participant expressed disappointment with the negative attitude of her parents. They never seemed to care about sending her to school to attain an education that could have

helped her to attain a good standard of living in the future. She attributed it to the fact that she looked different compared to the rest of her siblings. She said:

I am the only one in my family out of my seven pigmented siblings who doesn't go to school. My parents will always say that they don't have the necessary school fees for me (Brenda - FGD2, female, LL rural).

#### **4.2.3 Lack of Knowledge about Albinism**

Both the participants and their families were not knowledgeable about albinism. Most of the families did not receive counseling when the PWA was born. This resulted in the family not knowing that the condition of albinism requires special skin and eye care. As a result, most families did not seek clinical advice on the care of their children with albinism. Most of the participants came to know more about their own condition when the abductions and killings of PWA were publicized in the media.

Furthermore, commenting on the causes of albinism, twenty out of twenty-seven participants said that they came to know about the causes of albinism two years ago in 2016 after spending so many years in ignorance. Information about albinism was received by some of the participants through the dramas and sensitization programs that were organized by APAM and another NGO called Tiritonse. The participants from the male focus group discussion narrated the following:

We grew up without knowing what exactly albinism was, but recently, we came to know about it through the drama and sensitization program conducted by APAM and Tiritonse (Hope - individual interview, male – MCM).

I came to know about the use of lotion on my skin in just the past 6 months (May 2017) from Tiritonse. I did not know that my skin color was a condition that needs special care. I was living my life as anyone else does (Daniel - FDG1, male, LL rural).

When I was young, I used to suffer from headaches and malaria frequently. Some people thought that mosquitoes were attracted to my skin because of my condition. This was thought to be true up until Tiritonse conducted a program in our community educating us on albinism then I came to know more about my condition (Mary - FGD2, female, LL rural).

One participant expressed that a lack of knowledge about albinism as held by their family members affected the way that their parents took care of them, hence there were complications with their skin. It was also revealed that due to the lack of knowledge of the family members, the support available for persons with albinism was lacking. Families who were all pigmented with only one child with albinism struggled when it came to determining the best way of taking care of the child with albinism unlike the families whose parents and children both had albinism. The participants recounted:

I grew up with my parents who did not have enough information about albinism. I was the only person with albinism in my household. Sometimes, when I scratch my skin, some of my skin peels off and this causes additional pain and sores. My parents were helpless when it came to my condition (Happiness - individual interview, male – APAM rural area).

My family did not understand my condition because I was the only one with that condition in my entire village and in the surrounding villages too. My family were in a dilemma and they could not support me well due to my required needs as a person with albinism (Saul - FGD3, male, KAPRA – LL urban).

The participants noted that they had not been wearing protective clothing, especially hats and long-sleeved clothes, to take care of their skin. This was due to a lack of knowledge on how important the items are to their health, coupled with a fear of looking different from others.

We go to the hospital early in the morning and we put our hats in a bag or pocket. The nurses sometimes question us on why we are not wearing the hats. We feel that there is no sun heat and so there is no need for us to wear a hat (Rose- FGD2, female, LL rural)

Sometimes my parents would give me a hat to wear but, as you know, here we don't wear hats in schools so I was the only one wearing a hat. Most of my classmates were also interested in wearing it and I ended up not having it all the time! (Abraham - FGD3, male, KAPRA – LL urban).

A key informant also commented on the inadequate wearing of protective clothing by persons with albinism:

Persons with albinism wear inadequate clothing with much of their skin remaining unprotected from the sun which results in the development of skin cancer. Most PWAs cover their head and face while their neck and ears are exposed to the sun. (Key informant 1-APAM)

Furthermore, the participants noted that due to the lack of knowledge, sunscreen lotion was not effectively used on their skin:

My parents were not all that conversant with my condition [and the fact] that it needed special sunscreen lotion despite them both being teachers. At times, my skin used to have blisters that came and healed but I did not know it was because of the sun (Cynthia -individual interview, female - APAM).

A key informant attested that:

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

#### ***4.2.3.1 Beliefs***

The lack of knowledge about albinism in most of the families shows when they think that the condition is a result of being bewitched by their enemies in the community. There was a strong belief amongst the women with albinism that their condition was contributed to by the anemic condition that was experienced by their mothers during the pregnancy. Such beliefs further shatter the understanding of albinism, specifically the beliefs of the PWAs who were told that their mothers, in addition to anemia, had received a blood transfusion during childbirth. It was noted in this study that most of the women with albinism were born after their parents had given birth to other children without albinism. They had a strong belief that the first child/ren cleanse the womb of their mother, hence why the following children are born with albinism or lighter skin. With this type of belief among the PWAs and their families, it makes it difficult for them to understand that albinism requires special care when it comes to both their skin and eyes. In the view of the PWAs it was just a difference in the degree of skin color.

During the focus group discussions with the women, there was a strong emphasis by the participants that society can be evil and that people can do anything to their fellow human beings as a result of envy and jealousy. This led the participants to believe that their mothers were bewitched due to a misunderstanding in their clan or community. This notion was revealed through the responses that they gave when they were asked what albinism is:

‘Albinism is [a] difference in skin color (Rachel- FGD2, female, LL rural). Another participant added that ‘I think albinism is witchcraft-related. I suspect somebody did something to my mother when she was pregnant. That is why I was born like this’ (Sara - FGD3, KAPRA, LL Urban).

I am a 46-year old female and born to a family with eight siblings. I am the last born in the family and the only person with albinism. The first born in my family was very dark in complexion but the complexion of the other siblings kept changing to lighter skin. I was conceived when my parents were older... my complexion is lighter than anyone else in the family. That is why I strongly believe that albinism is as a result of being conceived when the parent is older. In most families, the last born is lighter in complexion than the first born, which was agreed on by all of the female participants. Only the degree of lightness differs. My first three children were born without albinism and the last two children were born with albinism (Ruth – FGD2, female, LL rural).

It was revealed by one participant during their in-depth interview that she thought that albinism was as a result of being born to an anemic mother. The participant had this to say:

I was told that my mother did not have enough blood when she was pregnant with me. My mother was anemic even when she was giving birth to me but by God’s grace, I survived. So I am not sure whether my albinism is related to a blood shortage from mother to child (Gladness - Individual Interview, female - APAM).

#### **4.2.4 Economic Challenges**

The persons with albinism residing in the rural areas who depended on farming were economically more affected as they lacked support. The participants noted that they experienced poverty because their condition does not allow them to work effectively, especially under the sun. Therefore, activities such as farming, which can expose them to the sun, are often practiced on a limited scale, thus they have insufficient resources such as finance, food and thus the inability to meet their basic needs. The participants mentioned that they must work early in the morning before the sun rises to avoid the heat, hence they are less

productive. In addition, pigmented people do not offer persons with albinism jobs as they think that they cannot work. The participants also said:

My work is limited when there is too much sun. For example, I am unable to participate in a community project called “food for work” where we help to clear the roads or we do community work to get food or cash. The work is done in a group of community members and we agree on the time to start the work, which is normally around 5am to 8 am. However, sometimes by 6:30am the sun is already too hot and I cannot manage to withstand the heat then I go home. Again, I cannot say that I will go earlier than my friends because my security is in danger. As a result, my economic status fails to improve and I continue to live in poverty because the community cannot keep on adding me on the project knowing that I cannot work effectively on the sun like others. (Thomas- FGD3, male, KAPRA – LL urban)

Living with albinism limits us economically. When we go to the farm because we cannot farm for longer hours due to the sun’s heat, we harvest very little crops which results in us having inadequate food reserves... (Ruth – FGD2, female, LL rural).

With poverty in our family, we just wait for death. No one is ready to give us work in their field. I don’t have anything to feed our family. It becomes so difficult to even find soap to wash our clothes with to enable the children go to school with clean uniforms. As a result, the children stay in the house extending the poverty to the future generation (Joshua – FGD1, male, LL urban).

It so difficult to get a casual job that can enable me to sustain my life. Sometime when I move around looking for a job, people think that I cannot do the work. Because of this, I normally get work from the people who know me very well although not on the usual occasions (Happiness - individual interview, male – APAM rural area).

Another participant who lost her sponsor revealed the pain that she experienced due to a lack of support. She noted that this sponsor was going to support her with a startup kit after the completion of her tailoring course but unfortunately, that was not the case. She lamented:

I was identified by a pastor who owned a tertiary school and they gave me a full scholarship because I did not have any source of income. Now this Pastor is dead and I have no hope in my future. I have tailoring skills but I do not have the money or the machines to do the work (Lovemore – individual interview, Male - APAM).

It was found in the study that some of the participants ended up unemployed due to low education qualifications. This caused them to envy their classmates who were doing well in society. A participant summarized:

... Most of our pigmented friends have secured very good jobs in town because they were able to do well in class while I was struggling with school and never succeeded. There makes a very big difference in our lives... (William - FGD1, male, LL rural).

The study found that some of the participants were prevented from continuing with school because of their skin and because their lips had blisters with pus which required proper and special hygienic care. Therefore, due to a lack of financial resources, people with albinism and their wider households often fail to acquire basic materials such as lotions and soap for bathing and washing their school uniforms:

It becomes so difficult to find soap to wash the clothes to enable the children go to school with clean uniforms. As a result, the children stay in the house until I get money for soap to wash their clothes and to bathe and for food (Mary - FGD2, female, LL rural).

#### **4.2.5 Stigma and Discrimination.**

People with albinism experience stigma and discrimination throughout their lives. This was explained through the terminologies used to refer to them, their isolation from both their family and community members and their lack of involvement in the community activities and decision making. This has been explained below.

##### ***4.2.5.1 Terminologies***

In many societies in Malawi, when a child is born, their name is given depending on the situation at that particular moment. Persons with albinism are not exempt from this practice. Right from birth when a child with albinism is delivered, most parents have unanswered questions and this is expressed in the names given to the child. Some of the names express the meaning of how the child was welcomed into the family. In such cases, some of the name meanings express bitterness such as “*Mwatitha*” which means “*you have finished us*” whilst others express the problems ahead for both the family and society, for example, “*Mabvuto*” which means “*Trouble.*” This is because the family is not aware of what the future holds for them when they have a child with albinism. Such names are also given to children with albinism when the mothers experience problems in their marriage as a result of giving birth to a child with albinism. Some men suspect that their wives have had a sexual relationship with a white man, hence the albinism of their child. However, some families gave loving names to their children with albinism such as *Chikondi (Love)*, *Chimwemwe (Happiness)* and *Mwai (Lucky)*.

People with albinism, when growing up in their homes, also receive extra names from their family members which has often replaced their given names such as “*Mzungu*” which means a “*white person.*” Although “*mzungu*” could sound pleasing when mentioned in a good and

loving way, at times it was mentioned in a derogatory manner. These generated negative emotions such as disappointment, frustration and anger when the demeaning names are given PWAs. Derogatory names were also given by their peers and community members. Most of the names were to do with their skin color being described as “*red*.” This is a total mockery of persons with albinism and it has made them feel discriminated and stigmatized against when they are found in the presence of people without albinism.

Furthermore, when society started to understand albinism and the stigma PWAs experienced as a result of demeaning names, it became more difficult to mention persons with albinism in the local language of Chichewa. This is as most people were not certain if using the term “*alubino*” would be acceptable. As a result, most people, in a bid to be on the safe side, would rather use a descriptive sentence than a single word. The same challenge was also experienced by the persons with albinism when expressing their preferred identification/name for themselves and for persons without albinism.

One participant revealed that his mother gave him a name to prove her innocence or to predict the uncertainty or trouble that both would have to face in the future because of his albinism. He narrated:

I asked my mother why she named me ‘Chiletso’ (meaning ‘forbid’ or ‘not welcomed’). She said that: I gave you that name to show my innocence... that I did not sleep with other foreign men. Your father told me to dump you because of your condition but I refused, thus giving you that name (Hope - individual interview, male – MCM).

When children grow up with such names, it makes them aware of the situation they are in. They become more defensive and upset with any additional names that other people may give

or call them by. The participants experienced negative emotions and anger when more demeaning names were given by other people, as noted below:

Growing up in my entire life, I felt very disappointed and frustrated when I was young because of the names that were given to me... At home, both the adults and children gave me derogatory names. (Faith - individual interview, female - MCM)

My friends started talking much about my skin color and the way that my eyes were moving. They started giving me names such as 'Kafide', 'Kafira' and 'Kadiri' (which means red or different from us). I used to be very angry when someone one called me one of those names (Thomas - FGD3, male, KAPRA – LL urban).

In addition to the above, this study had the challenge of finding the most appropriate terminology to refer to people with albinism. It was observed during the interviews that both the key informants and persons with albinism did not mention there to be one right local terminology used for albinism. Instead of formal terminology, descriptive statements were used instead to describe persons with albinism. The key informant said the following when referring to people with albinism: ... 'Anthu angati amenewa' is used which means 'people like these ones.' (Key Information 2 – KAPRA)

The participants who were persons with albinism themselves said they prefer anthu obadwa chonchife, which means 'people who are born like this (us)'... (Sandra - FGD3, KAPRA, LL Urban).

With the above terminology used to refer to persons with albinism, any slight mistake in terminology can easily upset their emotions. This was observed during the interviews between the participants and the researcher. Unintentionally, the researcher, at the start of the

interviews, interchanged the words “*persons with albinism*” and “*persons living with albinism.*” It irritated the participants. One of them noted:

I don't like to be referred to as a person living with albinism. The best way to address me is as a person with albinism because I did not acquire the condition after I was born and I cannot reverse it! (Cynthia -individual interview, female - APAM).

#### **4.2.5.2 Isolation**

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

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

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

My mother was invisibly excommunicated from the church because of my birth. Even now when she attends women's gatherings, the members will show through their body language that she is not welcome in the group (Joshua – FGD1, male, LL urban)

A key informant confirmed that:

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

The participants expressed the challenge and disgrace that they had encountered when they were looking for accommodation in high density areas in the city. It was revealed that some landlords do not want to accommodate people with albinism in their compounds. This was evidenced by one participant's response:

I was new to the community. My husband went to look for accommodation alone and he was offered a house. When we moved into the new house as a family, we were given back our money the following day and told to vacate immediately without any explanation (Thomas - FGD3, male, KAPRA – LL urban).

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

... when I enter into a shop where there are pigmented customers who are buying or asking for a price, some of them immediately stop the transaction and leave the moment that they see me entering the shop (Brenda - FGD2, female, LL rural).

Shop owners do not want us to enter in their shops because they know the other customers will leave. They will either chase us away when we try to enter the shop or they will wave their hand to signal us not to enter the shop... There are some shops that I have stopped going to (Rose- FGD2, female, LL rural).

Sometimes pigmented people skip me after I have extended my hand for a handshake deliberately. However, they will greet each freely and exchange handshake greetings in a social gathering ... (Thomas - FGD3, male, KAPRA – LL urban).

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

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

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

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

I have lived in the city of Lilongwe for my entire life, interacting freely with my neighbors and friends. However, the sudden killing of persons with albinism in Malawi in 2015 has affected my cordial relationship with my friends and the people who surround me. Most of my friends shy away from me

and I am now the center of attention in one way or another in my community because most of my community members and friends see me from a different angle. Some of my friends, who were bold enough, told me that they are afraid that the police may take/arrest them as suspects. This is because immediate friends are usually targeted and picked for investigations (Sandra - FGD3, female, KAPRA, LL Urban).

#### ***4.2.5.3 Lack of Involvement***

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

The government commemorated World Albinism Day and they spent millions of Kwachas in the form of allowances to delegates who are not even persons with albinism... but it does not consider us for startup capital or economic empowerment to enable us reach the same level as our fellow pigmented persons. We need to hear success stories, not T/Shirts (Sandra - FGD3, female, KAPRA, LL Urban).

There are a lot of programs that target persons with albinism and persons with disabilities on paper but nothing tangible is seen on the ground (Moses - FGD1, male, LL rural).

I have been living in the community ever since I was born. I have seen different projects both government and non-governmental in my community. I have tried my luck several times to participate in some of the projects such as food for work. This requires community members to clear their roads for payment or a bag of maize but I am always not picked. For that one, I thought that maybe the leaders were considering my condition versus the sun. What surprises me now is that even in other projects such as the project for HIV/AIDS, persons with albinism are not involved or included to make their own decisions. .... Women with albinism are at a high risk of being sexually abused such as by rape as people believe in the myths that sleeping with a woman with albinism can cure their HIV, yet we are excluded from programs like this. I feel that we must also benefit from the HIV/AIDS

programs. I feel that we are not involved because the program has monetary benefits. If it were free, they could have called us to join (Rachel- FGD2, female, LL rural).

A key informant added that:

Most organizations have not been involving PWAs in their programs. This may have been because various bodies, where PWA belong, do not advocate for them when it comes to benefiting from the existing community programs. There has been little awareness on the need to include PWAs in all programs. There are cases where the organizations are looking for PWAs to train but their bodies do not respond to the call. (Key Informant 3- MCM)

#### **4.2.6 Healthcare Challenges**

The people with albinism also indicated that they experienced various health challenges. These challenges included visual challenges, hearing problems, bleeding of the lips, skin problems, the non-availability of sun screen lotion, negative attitudes from the health personnel and the long distance to the health facility.

Regarding the visual challenges, the participants mentioned that when the sunlight was too much, they could not clearly see both objects and human beings unless they were in close proximity. They further noted that because of the visual acuity, they could see only shadows if they were not wearing glasses. They explained:

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

I have severe eye problem that worry me so much in my daily life. This is the reason why I have failed to progress in academia ... (Rose- FGD2, female, LL rural)

The hearing challenge was another issue that the participants mentioned. Some of the participants noted that they were able to hear very well if the one talking to them spoke with a high tone of voice. During the interviews, it was observed by the researcher that the participants turned their ears to clearly listen to what she was asking them. The participants said:

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

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

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

Throughout my life, I have been experiencing cracked lips and this worries me so much (Rachel- FGD2, female, LL rural).

Commenting further, evidence from the participants indicated that they faced skin-related challenges. This included feeling a burning pain on their skin when exposed to the sun, the development of blisters, the peeling of the skin and changes in skin color. Furthermore, some of the participants indicated that due to their sensitive skin, they were allergic to any soap that they tried to use. The participants attested:

Hmm, for us we go through a lot of problems. You see these skins of ours... they are affected by the sun. Sometimes you feel like somebody has poured hot water on you (Joshua – FGD1, male, LL urban).

You see how this skin color is? That is not how I looked before. It just started changing gradually. Even these sores on my body... I was told in the hospital that they are a result of my albinism. Other times, the skin just peels off by itself (Happiness - individual interview, male – APAM rural area).

My skin reacts to any soap I use to bathe. I develop a goosebump skin rash immediately. Because of this, I bathe without soap sometimes. I don't know the ideal soap for my skin type (Saul - FGD3, male, KAPRA, LL Urban).

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

You can see for yourself how rural our community is. We do not have any big health facilities that are equipped with the cream they tell us to use. So for some of us who cannot travel to the government central hospital to collect the cream for free, it becomes too hard for us to take care of our delicate skin (Brenda - FGD2, female, LL rural).

Sometimes I am forced to use lotions such as Johnson and Johnson because there are no cheaper sunscreen lotions. The lotions drain much of our resources (Joy - Individual Interview, male, - MCM).

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

The findings also showed that the participants experienced a poor reception and attitude from the health personnel when they visited the health clinics, contributing to their low attendance on the clinic days. The participants said:

When we go to the central hospital to get medicine and the skin lotion, we encounter a lot of challenges from the health personnel such as ridicule and shouting... (Daniel - FDG1, male, LL rural).

Eeee, you have to get prepared psychologically and be strong as the medical personnel will shout at you and even sometimes treat you like a nobody. Otherwise, you may end up coming back home empty-handed without the medication (James - FGD3, Male, KAPRA- LL urban).

Finally, most of the participants complained of the long journey that they must embark on when going to the health facilities that provide skin care services, which are located in major hospitals only. PWAs are required to visit a skin clinic every month to undergo a routine skin review in order to detect the early signs of skin cancer. The health facilities within their communities do not provide the skin care services that are required for their skin type and most health facilities do not have qualified dermatologists in the rural hospitals. As a result, most of the time they are referred to the major central hospitals for further treatment. This increases the transport expenditure of the already vulnerable and poor individuals. The participants said:

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

A key informant had this to say on transport challenges:

The majority of persons with albinism do not receive any cancer prevention and treatment services including accessing essential sunscreen lotion because of the distance to the health facilities (Key Informant 1- APAM).

#### **4.2.7 Emotional Issues**

Numerous emotional challenges including fear, bitterness and marriage breakups were reported by the persons with albinism in this study. These emotional challenges have been explained below.

##### **4.2.7.1 Fear**

The participants mentioned that they experience fear due to the wave of violent deaths that has been happening in the country. They revealed that it is now getting very hard to feel safe and to trust people because some of the victims who were killed were given up to the killers by their own relatives who gave them crucial information about them. One participant said that:

We always have to be careful with our lives because the same people you go with to cut and forage can bend up against you in the bush (Janet - FGD2, female, LL rural).

I don't have enough security. I am always afraid of people... of nearly everyone. These days I cannot go about freely as before... (Sandra - FGD3, female, KAPRA, LL Urban).

Most of the participants in the focus group discussions said that before their albinism was brought into the limelight by the media, they survived and lived normal lives like anyone else in their community. However, the unwarranted killing of innocent persons with albinism has brought fear into their social lives. Some participants expressed:

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

When the news broke that persons with albinism are being killed, I immediately stopped working in a big company as a mechanic. I left the city and rushed to the village because my parents were calling me... saying that I should leave everything and come back home for safety (Joy - Individual Interview, male, - MCM).

Additionally, a key informant noted that news of the killings has further contributed to fear among the community members. They are afraid to report cases involving persons with albinism to the police as noted below:

Individuals are afraid to report cases involving persons with albinism to the police because of the fear of being arrested or being considered a suspect (Key Informant 2 - KAPRA)

Most participants said that the killings have brought fear and anxiety to the families of persons with albinism and they do not have peace, especially when there is news of more killings. The participants said that their parents and relatives have become worried, especially when they are not around and not picking their calls. The participants said that:

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

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

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

#### **4.2.6.2 Bitterness**

Some of the participants mentioned that they experience bitterness because of having albinism. Some expressed suicidal thoughts due to the struggle that they experience as a result of this condition:

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

Other persons with albinism did not believe that God had made them that way. They attributed their condition to being a punishment from God or as an act by evil men who they associate with witchcraft. The participants said:

I don't believe that God made me this way. I strongly believe that it was an act of envy from evil men that made me look like this (David – FGD1, male, LL rural).

Growing up with albinism is a challenge. It's like a punishment or a curse from God for something that my parents or the village did wrong (Gladness - Individual Interview, female - APAM).

The study found that bitterness left many unanswered questions for the persons with albinism. This was especially prevalent in families and communities where there was only one person with albinism among pigmented people. One participant said that he feels that he fails to connect with his family due to the mismatch that he felt was too much to bear. He narrated that:

Growing up as a person with albinism has not been easy for me. I always have unanswered questions on why it is only me in my family and the surrounding communities. Everything about me is different from others... I used to ask myself if indeed these were my parents as there was nothing that was connecting me with them (Saul - FGD3, male, KAPRA – LL urban).

#### ***4.2.7.3. Marriage breakup***

Some of the female participants experienced marital turbulence due to the birth of a child with albinism. Most births resulted in abandonment, rejection and insults. The participants revealed that in most instances, the women were left with the responsibility of taking care of the child with albinism alone. Some of the fathers of children born with albinism abandoned their homes for other women and never took further responsibility of the care of the children:

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

When my mother gave birth to a second son who is my elder brother, my mother did not have peace in her marriage because my brother had albinism. She experienced rejection and insults from my father and the entire clan (Brenda - FGD2, female, LL rural).

... my father lives in the same city where I live but he has never visited me. I am the only one who visits him. It pains me because it made me grow up like a fatherless child. My father has never bothered to assist with my school fees and welfare (Thomas - FGD3, male, KAPRA – LL urban).

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

... My spouse was too afraid of being accused of conniving with the thugs, so he left (Abraham - FGD3, male, KAPRA – LL urban).

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

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

#### **4.3 Coping Mechanisms of Persons with Albinism**

Persons with albinism have adopted several coping strategies when dealing with the challenges that they experience as a result of their condition. Nine themes emerged which include awareness programs, advocacy and confrontation, withdrawal, support, personal development and care, health care and record keeping, security, networking and acceptance.

#### 4.3.1 Awareness Programs

Most of the participants confirmed that different organizations have brought awareness programs into their communities. This was a result of the killing of persons with albinism by people in a macabre business. The awareness programs have helped persons with albinism to know that their skin color is a genetic condition and that with the proper care, they can live a meaningful life. The participants narrated that:

We grew up without knowing what actually albinism was. We have just come to know about the condition recently through the drama and sensitization programs by an organization called Tiritonse. At first, we thought that it was just a different skin color from others in our community (Solomon-FGD1, male, LL rural).

Before the wave of killings of persons with albinism that was going on in Malawi, most of us did not know anything about the causes of albinism and how to take care of ourselves. However, organizations such as Disabled Women in Africa (DIWA), APAM and Tiritonse came to educate us (Rose- FGD2, female, LL rural)

Despite the unfortunate trend of attacking persons with albinism and its negative impact, it has also brought to light to the lives of persons with albinism as we were living in the dark. Organizations have now come forward to educate us on how to take care of our skin and how to use sunscreen lotion with a good sun protection factor (Faith - individual interview, female - MCM).

Some of the participants mentioned that the support rendered to them by the organizations in terms of providing skin lotion has helped them to experience a new life with an improved skin texture, from having no lesions to having supple skin:

Being the most hated people in our society... it could be that was due to the way that our skin looked before since it had a lot of lesions. Now, things have changed because our skin has improved and we look more handsome than before (Joseph - FGD1, male, LL rural).

The participants also identified that the availability of missionaries from Western countries in some of the rural areas where they resided has helped the parents of children with albinism get support when caring for them in the early stages of their life. In addition, the dedication of the missionaries to educate the participants on albinism and to support them with sunscreen lotion has helped them to deal with the distance challenges and also to live a fuller life without skin problems.

My parents were given information about albinism by the Canadian missionaries ... These people also solicited sunscreen lotion from their counterparts in Canada and they are the ones who helped to sponsor my education (Thomas - FGD3, male, KAPRA – LL urban)

Furthermore, some of the participants indicated that knowing how to live better with a fulfilling life despite their condition has made them proud. These people were also found to be successful in life and they acted as role models for their friends both with and without albinism.

Actually, I feel proud of myself and my condition because I know that I can live a normal life like any other person if I take care of myself very well... Even though we are in a minority group, these days we are being used in advertisements which has made us celebrities (Abraham - FGD3, male, KAPRA – LL urban).

I have never regretted being born with albinism. I am proud of the way that I was born, as it was God's will and it cannot be changed by anyone (Sandra - FGD3, female, KAPRA, LL Urban).

A lot of people admire my skin these days. My skin looks so supple and unique. I always encourage my friends with albinism when we meet for our routine checkups and gatherings that we have unique skin and that we need to take good care of it so then people can appreciate us. I also tell them that the love of our condition begins with us (Moses - FGD1, male, LL rural).

A participant cited that due to the current awareness programs in place for persons with albinism, organizations are now helping women who are divorced and left with the responsibility of taking care of their children alone when it comes to seeking a redress in the court of law:

I was divorced from my marriage and DIWA helped me to claim the damages from my husband to give support to our children. Also the community members were supportive of our welfare by quickly taking action if we were maltreated by our spouses (Janet - FGD2, female, LL rural).

Awareness programs and the support provided by the different stakeholders involved have helped persons with albinism to become more vigilant about any sudden social changes in society. The participants mentioned that:

The interventions by the NGOs and the government have helped to inform us of the killings that are taking place in town. The information has helped us to be vigilant and careful in our endeavors (Rose- FGD2, female, LL rural).

The torches and whistles that were given to us by DIWA have helped us to have light both in our houses and when we are walking outside in the dark. At least this enables us feel secure at night (Mary - FGD2, female, LL rural).

#### **4.3.2 Advocacy and Confrontation**

The participants indicated that they coped by confronting those who were fond of ridiculing them. The persons with albinism noted that they threatened to report the perpetrators to the police, coupled with giving them information about albinism and how they are supposed to treat people with this condition. In the end, this acted as individual advocacy on the part of the participants as it helped them to educate the other participants who in turn educated others about albinism.

A friend told me that he will sell me. I was so furious and I took it serious. I advised him not to say that again to anyone with albinism because they will report him to the police... Also there is one person who started calling me names that were demeaning. I was able to teach him about albinism and this changed his attitude towards us. Now he is teaching other people about albinism since he was harassing me out of ignorance (Solomon - FGD1, male, LL rural).

#### **4.3.3 Withdrawal**

An emotional participant mentioned that the exhuming and dismembering of her dead child with albinism the day after he was buried left her with bitterness and hatred. Since then, she no longer attends social gatherings and funerals:

When my son aged 10 died, he was buried in the community cemetery. It was to our shock after a day when community members started coming, telling my family that the body of our son has been exhumed and that some of the body parts have been removed. They were asking us to go for a reburial but we refused. How can I bury my son twice? Since it's a dead body, I told them to let those who exhumed him rebury him. Since the incident occurred in 2016, I don't go to the graveyard when there is a funeral in the community because I don't want to see my son's new grave again. I don't have anything to do with any social activity in my community since I feel bitter and hate everyone (Janet - FGD2, female, LL rural).

Some of the participants said that because of the bitterness and rejection of their albinism condition, it has made them feel isolated. It was their choice to be reserved so then they cannot easily be noticed. This situation means that they do not fully enjoy their life compared to pigmented persons.

I regret being born with albinism because I do not enjoy my life fully like others without albinism. I always feel reserved as though am in the wrong place all the time (Saul - FGD3, male, KAPRA – LL urban).

#### **4.3.4 Support**

Some of the participants indicated that since their parents were conversant with their condition and its needs, they supported them with their academic work at home. This helped them do well academically and they were also found to have better careers in their adult years. The participants helped them to improve their financial status when they sold the finished products. The participants also indicated that the new skills complimented their missed academic years:

I interact with other women where am able to learn some skills in cookery, knitting and socialization. This has helped me generate some finances to use to meet some of my basic needs (Gladness - Individual Interview, female - APAM).

The participants further noted that they received support from their friends and well-wishers in the form of tangible materials such as hats and clothes, thus helping them to have the required protective clothing. They also indicated that they received information on personal security, especially from the local leaders. This helped them to cope with the challenges of insecurity. They narrated this in their own words:

At times, good Samaritans help me with brim hats and long-sleeved clothes which have been helpful when it comes to protecting my skin (Mary - FGD2, female, LL rural).

Traditional leaders have tried to inform persons with albinism and their relatives of the available security that can be helpful in case our human rights are abused. Now at least we can feel secure and live in our own country without fear. The only challenge is that they do not include us when solving the other problems that we face (Ruth – FGD2, female, LL rural).

According to some of the participants, support from their spouses who were working in institutions or doing business was helpful when it came to sustaining their family and meeting their basic needs. This made the participants happy as they felt that they were still loved and provided for, unlike other persons with albinism who are neglected:

I am lucky that I still get support from my husband who works in an institution as a salaried worker. He buys everything such as fertilizer and goats, and he pays for the house rent (Rachel- FGD2, female, LL rural).

I get my support from my husband who earns a salary at work and who fixes bicycles on a part-time basis. With that, I know that I cannot sleep hungry with my children and I do not have to beg from people (Janet - FGD2, female, LL rural).

#### **4.3.5 Personal Development and Care**

Narrating their experiences, some of the participants indicated that after experiencing challenges related to securing jobs and seeing some of their friends with the same condition excelling in their careers, they decided to further their studies. This was meant to improve their academic grades so then they could also earn a good living. The study found that with good academic grades, persons with albinism are able to secure good jobs:

I would like to re-sit my secondary school examinations to obtain good results so then I can get a good paying job. I am tired of repairing bicycles because there is no money in it to sustain myself... (Sandra - FGD3, KAPRA, LL Urban).

For me, I just went back to studying at university after a hard life hit me. I was determined to learn no matter what because I wanted to live a better and decent life like others... although it was not an easy path as the letters were very tiny and I had to use binoculars to assist me with my reading (Cynthia - individual interview, female - APAM).

Some of the participants felt that it was their responsibility to protect and take good care of their skin.

... I earn a good salary and I am comfortable buying my own sunscreen lotion with a higher SPF if I cannot get it for free. My life and health is more valuable to me than anything else (Cynthia -individual interview, female - APAM).

Some of the participants revealed that issues with skin color are complicated at times depending on the beliefs and attitudes of the people that surround them in that moment. It was reported by the participants that some pigmented persons are receptive to anything that a white man does or says. This was experienced by a participant working in a hospital who got mistaken for a white doctor. This participant further said that when working on the patients, they opened up freely, unlike those who based their assumptions that nothing good can come from persons with albinism.

In some wards, patients mistook me for a white doctor and others are afraid... However, there are those who trust me when I attend to them (Cynthia -individual interview, female - APAM).

Furthermore, while all of the participants' mention eye problems, some of them were able to overcome the challenge through surgery and the use of eye glasses. ...my eyesight problem was rectified by surgery (Lovemore – individual interview, Male - APAM).

I experience pain in my eyes, but now the school has given me tinted sunglasses that are helping to solve my problem (Saul - FGD3, male, KAPRA, LL Urban).

Because of the eye problem, I cannot see well and I experience a sharp light. I wear glasses to help with my condition. Without glasses, I cannot see a person who is very far from me and sometimes even when they are near. I only see the figure but I cannot recognize the face well (Sara - FGD3, KAPRA, LL Urban).

#### **4.3.6 Health care and record management**

According to a participant, it was revealed that persons with albinism cope well when they are well informed of their condition and advised on the benefits of visiting hospitals for the routine screening of their skin:

I received counseling on the benefits of taking good care of my skin by using sunscreen lotion and the medical doctor also screened my skin thoroughly... The person had more time with me (David – FGD1, male, LL rural).

The study found that record keeping through a unique identifier on the personal file of persons with albinism at the skin clinics helps the clinic to following up concerning the attendance. This helps the hospitals and persons with albinism to access the treatment needed at any hospital in the country. The system also helps the medical personnel in other areas to easily access the information and history of the patient. The key informant said:

When persons with albinism visit the hospital, they follow the normal procedure at the clinic, whereby they stand on the same line as pigmented individuals until they reach the point of seeing the doctor. However, the records of persons with albinism have a unique identifier which helps the medical personnel to treat them accordingly. The unique identifier also helps to stop the PWAs from collecting sunscreen lotion and zinc on behalf of their friends. The system allows each and every one to be attended by the medical doctor on a one-to-one basis (Key Informant 1- APAM).

Some of the participants asserted that in other mission hospitals, especially those in the rural areas, the parents were allowed to collect the sunscreen lotion on behalf of their children. This allowed the school-going children to concentrate on their studies as most of the clinics were conducted on weekdays.

...my parents were allowed to collect sunscreen lotion on my behalf, provided [hat they went with my health passport (James - FGD3, Male, KAPRA- LL urban).

It was revealed by the key informant that apart from record management at the skin clinics, the Police Support Victim Unit in liaison with community policing has put in place mechanisms for registering all persons with albinism in the communities through their traditional leaders. During the process, it was noted that counseling services are also provided to persons with albinism and their family members:

The Community Police, together with the local leaders, report and register any birth of a child with albinism in their communities. Counseling on the best care of the child and routine follow-ups are conducted by both the police and traditional leaders (Key Information 2 - KAPRA).

#### **4.3.7 Security**

Persons with albinism encounter threats, abduction and they are even killed for their body parts by their fellow human beings. In a bid to protect themselves from these attacks, some

protective measures enacted by the police and individuals have been put in place. It was found that collective efforts by the community members, their family and the police have gone a step further in terms of monitoring and safeguarding the movements of the persons with albinism. The participants commented:

My family, community together with the police always makes sure that they know my whereabouts. There is a follow-up exercise being conducted by the community police (Happiness - individual interview, male – APAM rural area).

Some community members, when they see me roaming around at late hours, become concerned and they ask me to rush home. Some will escort me to make sure that I am safely home (Sandra - FGD3, KAPRA, LL Urban).

The community updates me with the current news regarding persons with albinism (Gladness - Individual Interview, female - APAM).

One participant indicated that together with his mother, they fight for their human rights:

My albinism has made my mother very stubborn. She will fight anyone who tries to make fun of my condition (Joshua – FGD1, male, LL urban)

It was reported by one of the participants that in order for her to enhance her security against attackers, she moves with a group or with other family members, especially relatives, for protection. She revealed that when leaving the home, her family members take note of the people that she leaves with.

...When there is a funeral or social gathering in the community, we go as a group... so, my protection is my friends and family members (Ruth – FGD2, female, LL rural).

According to the key informant from the Police, she explained that when the Community Police team finds out about the parents who are afraid of community ridicule and hide their children, they assure them of their support. They are also encouraged to bring their children out and to report any security threat that they encounter.

The parents who hide their children in the house once found are cautioned and counseled together with their family to help them to overcome any of the challenges that they might be facing in the community or at home (Key Information 2 - KAPRA).

Most of the participants expressed their happiness as they have seen the law take action against offenders, especially those who calling persons with albinism demeaning names. This is a result of the statements made by the President and Inspector General of Police (IGP) regarding the protection and abolishment of ridiculing words used to refer to persons with albinism:

The IGP made a strong statement that those who make silly comments about us and also those who whisper or shout at ‘dhiru’ or ‘million’ at me... They need to stop or they will risk being punished by law. When people started hearing the news that the continuous naming and harassment of persons with albinism may lead them to being in jail, most of them stopped because they had seen or heard of people being jailed for calling persons with albinism ‘dhiru’ or ‘million’ (Abraham - FGD3, male, KAPRA – LL urban).

#### **4.3.8 Networking and Peer Support**

Some of the participants stated that the Thursday meetings at the skin clinic provided a sense of belonging because they were able to meet their friends with the same condition. These meetings also established networks and provided opportunities for sharing experiences about

their condition and empowerment. This helped most of the participants to be united as a group and to get registered as APAM members.

When I visit the skin clinic, I make a lot of friends and we discuss how to take good care of ourselves. APAM volunteers conduct the counseling sessions with us and we feel that we are free to ask about any skin problems that we face (James - FGD3, Male, KAPRA- LL urban).

#### **4.3.9 Acceptance**

The participants said that in most homes, it took a long time for the fathers to come to terms and understand the albinism of their children. Most of the participants confirmed that in their lived experiences, most of them had little attachment to their fathers compared to their mothers. This was dependent on the love and care that they got from both parents and other extended family members:

My father did not accept me at first as his child. He had a lot of misunderstandings with my mother. He wasn't sure if I was his child but deep down in his heart, he knew I was his child. He could not take me out or have anything to do with me. He was avoiding me as much as possible. His parents told him that one of his grandparents had albinism. My father had to slowly adjust to understanding my condition because I was the only one with albinism in the family (Lovemore – individual interview, Male - APAM).

My immediate family has accepted me as a gift from God. They are always proud of me and treat me as their flower in the house. Everyone loves me so much. I enjoy the love from all of my clan members (William - FGD1, male, LL rural).

It was revealed by the participants that some of their mothers were heartbroken upon giving birth to them. However, they got encouragement and assistance from the missionaries within their communities who were able to assist them in caring for the child in the early stages:

...my mother was heartbroken when she gave birth to me because she was not sure what people will say about her and me. However, she was able to overcome it with the help of the missionaries who used to visit her regularly with soap, baby powder and special lotions (James- FGD3, Male, KAPRA-LL urban).

However, some of the mothers who were facing ridicule and stigma sent their children with albinism away from the household. Some of the family members residing in the city offered their support by caring for their sisters' children. The PWAs were thus able to experience love in a new environment. This was confirmed by the participants who said that:

I grew up with my aunt and she treated me so well and equal to her other pigmented children. I was sent to stay with my aunt in the city because the people in the village were treating me badly while in the city, they were all excited to have me around them (Thomas - FGD3, male, KAPRA – LL urban)

Furthermore, in communities where they do not stigmatize or sideline persons with albinism, the participants were involved in community development projects alongside everyone else without prejudice. The participants said that:

I do community development work such as food for work and cash for work. During the school block construction, I helped by fetching water for the builders to mold bricks for school projects as part of a community contribution with other women (Sara - FGD3, KAPRA, LL Urban).

Food for work is a government project for community empowerment and it helps us to get cash through work... We clear the weeds on the roads to make the roads accessible after the rainy season as directed by our chiefs (Aaron - FGD1, male, LL rural).

In addition, some of the participants mentioned that they cope by involving themselves in church activities. This is because they were not segregated by their fellow church members and the groups to which they belonged:

I enjoy participating in most of the group activities in my church. Because of this, I am a member of the women's group and I am also in the women's choir (Abraham- FGD3, male, KAPRA – LL urban).

I am a choir master in my church. I teach my church members how to sing well and I also play piano and guitar (Saul- FGD3, male, KAPRA – LL urban).

#### **4.4 Possible Ways of Improving the Lives of Persons with Albinism**

The persons with albinism approached in this study made some recommendations on the possible ways that their lives can be improved. These are efforts that can be implemented by themselves, by the government and by non-governmental organizations (NGOs). The provision of financial support and the formation of clubs and NGOs specific for people with albinism were the themes that emerged.

##### **4.4.1 Provision of Financial Support**

Most of the participants reported that the provision of money by their parents on a monthly basis to go to the hospital to collect sunscreen lotion could help them to detect the early signs of skin cancer:

If the families were responsible or knowledgeable enough to provide transport money for their relatives to go to the hospital to collect the lotion, then maybe the challenge of skin cancer could be minimized (Faith - individual interview, female - MCM).

The participants also indicated that the organizers of different programs that aim to reach them should include transport and per diem in their budget, and that they should also manage their time better:

We walk long distances to attend the training and awareness campaigns, yet we are not given transport money (Ruth – FGD2, female, LL rural).

...when the NGOs and government officials call us for meetings, they should consider giving us some allowance rather than giving us nothing when they call us, yet they are on per diem... We adhere by attending the meetings but most of us come from different villages and very far away. Sometimes we have to hire bicycles (Janet- FGD2, female, LL rural).

An NGO called Diwa called us for a meeting starting at 7 am and end at 2pm. They gave us MK500 (US\$0.48) as an allowance, which was very little. Even if it was a government meeting or official, can they give their participants that small of an amount for the whole day? (Joshua – FGD1, male, LL urban)

It was confirmed by some of the participants that micro-finance institutions do not offer them loans because they lack collateral. However, the participants felt that if they could be considered for soft loans, then they could establish businesses to enable them to work in the shade and to become productive in society:

... Financial institutions such as micro-finance are not willing to offer loans to persons with albinism because we are considered already to be of low income status. They think that we cannot manage to pay back the loan (Cynthia -individual interview, female - APAM).

I am in need of financial assistance to help me start a business. However, it is difficult for me to get one because those who lend money know that I do not have any proper surety to show in case I fail to pay back the loan (Lovemore – individual interview, Male - APAM).

#### **4.4.2 Formation of Clubs and Specific NGOs for Persons with Albinism**

The formation of a group that will allow them to conduct business as a team under shade was suggested by the female participants from one of the focus group discussions. They said that this was the best way to enable them to be productive. The participants also indicated that these clubs could help them to hold meetings that can allow them to share ideas and plan their way forward:

We are planning to meet regularly to discuss the issues that affect us as a team and we will seek to overcome them. We also plan to start a project whereby we can mold bricks as a team for each one of us to build houses, then we will ask the government to help by including us in the current iron sheet subsidy program (Aaron - FGD1, male, LL rural).

... as women with albinism in our area, we are in a process of forming our own club like a village bank that will help us identify if a business such as a maize mill will help us to earn something as a group (Janet - FGD2, female, LL rural).

Most of the participants indicated that they don't know which groups they really belong to. This is because most groups do not give them a chance to be part of them. The participants suggested that they need to belong to a well-established group in order to meet their needs.

Most of the groups, when we want to join... they say we don't qualify. For instance, for HIV/AIDS, they say we don't have HIV/AIDS... for other groups or that we are not elderly or that we are not orphans. Even in the persons with a disability group, we are told that we do not have a disability. They ask us to prove to them that we have a disability, and so we are left out like that (Brenda- FGD2, female, LL rural).

Most of the participants observed that apart from APAM, most organizations do not have an interest in understanding their condition in the same way they do other conditions, including finding better solutions on their behalf:

There is no organization of pigmented persons which is concerned with the welfare of persons with albinism. You will hear them talking on HIV/AIDS, Sickle cell, persons with disability, Human rights, gender, but no one will mention persons with albinism (Faith - individual interview, female - MCM)

Some of the participants complained that the awareness programs are conducted in areas close to the city and on TV, yet most persons with albinism reside in very rural areas where they do not have access to television and radios. Therefore, the participants believe that if the proper means can be established to reach out to their fellow friends with albinism in very rural areas, then this knowledge could help to extend their lifespan.

Awareness programs are mainly for those who live in the cities. In my village, people do not know the best care to offer to their children with albinism. I visited one family and the condition of the children was so pathetic (David – FGD1, male, LL rural).

You see, most presentations on albinism are made on television, radio, and newspapers. A lot of people in the rural areas do not have electricity and these gadgets, hence they are missing out on this important information (Faith - individual interview, female - MCM).

#### **4.5 Discussion of Findings**

The findings of this study indicate that the persons with albinism encountered challenges in relation to their education in various ways. This was due to having difficulty reading the textbooks and the blackboard because of their poor eye sight. Poor hygiene was another challenge due to the lack of basic materials like soap to bath with and the washing of their

school uniforms. The bullying they received, including being called demeaning names by their teachers and peers, affected their self-esteem and confidence.

All of these factors lead the persons with albinism to performing poorly in class or even dropping out of school. The findings support those by Wan (2003) and Hong et al. (2006) who found that both teachers and students were the source of mockery and derision that left the persons with albinism feeling lonely and isolated. The author further noted that psychological and physical victimization, such as bullying and name calling from other students, worsened their experience in school.

The findings of this study also reveal that most persons with albinism end up not being in formal employment due to having a poor educational attainment that directly results from their condition. As a result, most of them experience financial restraints, even though some engage in petty jobs like bicycle repairing and small-scale farming, among others.

Additionally, it was found that persons with albinism, together with their families, lacked general knowledge on the albinism condition. It was identified by the participants that they did not know what causes albinism. However, most of them stated that albinism was a result of envy, jealousy and misunderstanding in the clan or community, leading the pregnant mothers to being bewitched. Others also noted that albinism is a result of being born to an anemic mother. These varied beliefs affected how the parents, especially the pigmented ones, took care of their children with albinism. Many did not take the time to learn how to properly care for their children in terms of providing them with protective clothing and sun screen lotion, resulting in skin complications. Furthermore, it is surprising that in the current study, some of the participants indicated that they had got information about albinism two years ago

in 2016 from organizations such as APAM and Tiritonse. These findings are in line with the studies conducted by Braathen and Ingstad (2006) and Cruz-Inigo et al. (2011) which found that many persons with albinism do not fully understand their own condition and therefore they lack knowledge related to what special aids they need in order to function daily. This lack of knowledge meant that there was a lack of vital items needed to function such as protective clothing, sunscreen and visual aids.

In the current study, it was observed that the families of persons with albinism lacked knowledge on the characteristics of albinism. This was observed during the individual interviews that were conducted in the homes of persons with albinism. Most of the family members had either a whitish eye color or sandy brown hair with slightly dark skin. However, they only referred to one or two persons in their homes who had very light skin as being persons with albinism. This lack of knowledge could have led to the ineffective care of their condition which may contribute to the late detection of health challenges such as eye problems and skin cancers. These problems could have been prevented if they knew that they also had the other type of the condition of albinism.

The findings established that persons with albinism are affected economically due to a lack of well-paying jobs and businesses that can generate a sufficient income. As a result, most of the participants live in abject poverty and are not able to meet their basic needs. Furthermore, their vulnerability is compounded by their condition which limits them when it comes to working effectively, especially under the sun. For those who go into farming as a source of income, their productivity is compromised as they work against the common shift times in order to avoid the sun's rays. To make matters worse, some persons with albinism lose out on job opportunities because of the stereotype that they cannot work. This is evident in the

work of Bines and Lei (2011) which found that PWAs are disproportionately more affected by poverty than other socially disadvantaged groups due to historical exclusion.

The current study found that persons with albinism experience stigma and discrimination in various ways which affects their social and psychological wellbeing. It was identified that certain terminologies that are used to describe the participants were unpleasant to them, for example, ‘Kafide,’ ‘Kafira’ and ‘Kadiri’ (meaning red or different from us). Additionally, this study faced a challenge concerning the local terminology that was most appropriate to use for persons with albinism during the interviews. Descriptive statements like ‘Anthuangatiamenewa’ which means ‘people like these ones’ were used by the participants to describe persons with albinism.

During the interviews conducted in English, the researcher mistakenly interchanged the words “persons with albinism” and “persons living with albinism.” This caused some of the participants to feel upset because they were more comfortable being called ‘persons with albinism’ (PWA). This finding is further in line with that of the United Nations (2016), which found that the term ‘person with albinism’ is appropriate because it puts the individual before the condition. These findings relate to those in Bourdieu's ( 2001) study which state that labeling persons with albinism circulated emotions of fear, hatred, disgust, shame, pain and ambivalence. The findings are similar to those of Baker et al. (2010) who found that describing people with albinism as ‘black’ was problematic, given their visible differences to other black Africans.

It was indicated that most of the names given to participants at birth had meanings that were attached to the situation into which they were born. The names also reflected how unpleasant

the parents felt concerning the kind of child that they had given birth to. Chisoni which means ‘Sorrow’ and Misozi which means ‘Tears’ were a few of the names shared by the participants.

Further evidence in the study showed that persons with albinism and their mothers were isolated by their families, church and communities. In the family, the participants were segregated from the rest of their family members who avoided sharing utensils with them like spoons, plates and cups because they thought that the PWA’s condition was contagious. When it came to the churches they attended, people were not comfortable interacting or sitting close to them. In the communities, the landlords feared giving the PWAs accommodation because they thought that they would lose other tenants. Isolation was further experienced by the participants when in public places like the market, shops and at social gatherings like funerals and weddings. People feared rubbing shoulders or even shaking hands with them.

These experiences left them in a lot of pain and experiencing humiliation. The current findings corroborate the finding of Lund et al. (2007) who found that some people believed that if one shared items like utensils or had any physical contact with persons with albinism, then he or she would go on to develop the condition. It further supports Chu's (2015) study which noted that there were dangerous misconceptions including that the mother of a PWA was impregnated by a white man, that the devil had replaced the child with an albino and that albinism is contagious, resulting in both the mother and child being marginalized.

Health-wise, the study established that persons with albinism face visual challenges, hearing problems, bleeding of the lips, skin conditions, the non-availability of sun screen lotion,

negative attitudes from the health personnel and there being a long distance to the health facility. The visual, hearing, and skin challenges limited the participants when it came to engaging in productive activities that occur in the sun. This is because the sun results in visual impairment and blisters on the skin. Although the bleeding of the lips was not common for everyone, those who experienced it felt a lot of pain and often became anemic, which worsened their health condition.

The vulnerability of persons with albinism, especially those in the rural areas, was worsened by the lack of sun screen lotion. Lotions are mainly available in the central hospitals located in the city. Therefore, due to the long distance from the rural area to the central hospitals, most participants found an alternative, such as buying cheaper lotions that are not recommended for them by health professionals. This action was also because of the lack of money to travel to and from the central hospitals. The study findings noted that when the participants visited the health facilities, the reception they received from the health professionals was poor due to the negative perception and attitudes about albinism. This, in the end, reduced the number of persons with albinism who visited the hospital during the skin clinic days. The above health challenges experienced by PWAs have been reported in the previous studies by Braathen and Ingstad (2006), Christensen et al (2017), Cruz-Inigo et al (2011), Nyamu (2014) and Wan (2003).

The emotional challenges identified in the current study were fear, bitterness and marriage dissolution. The killings in Malawi brought in fear among the participants, their family and the community members. Persons with albinism reported that that they lost trust both in their family and in the community members who they thought could have selfish interests leading to harm befalling them. On the other hand, their family members, especially their spouses and

the community, feared interacting with the participants because they thought that they would be suspected of a crime in case anything happened to the person with albinism. The findings also indicated that the families of the participants often experienced fear and anxiety especially when the killings happened in their communities, resulting in the restriction of the movements of their relatives with albinism.

The killings deterred some of the participants from getting married. This dilemma limited the social wellbeing of persons with albinism and the people around them. This is consistent with the findings of Mutasa (2013) who found out that some of the psychosocial challenges confronting persons with albinism manifest themselves through the marriage institution. Some find that it is complicated to establish a steady marriage owing to the myths and misconceptions aggravated by a society that is yet to entirely comprehend their condition.

Another emotional challenge noted by the participants was bitterness, which resulted from them not being happy about their albinism condition. Most often, they had many unanswered questions as to why they looked different and were therefore treated differently from the rest of their family members. They also blamed their parents and community members for being the cause of their condition. Furthermore, failed marriages, especially voiced by the female participants, left them emotionally affected. Giving birth to a child with albinism resulted in abandonment, rejection and insults from their spouses and families. This left the burden of responsibility on the mothers as they had to raise their abandoned children alone.

The above findings concur with those of Masanja, Mvena and Kayunze (2014), where due to negative attitudes, persons with albinism suffer rejection by the community and their family, and they are killed for their body parts. This further agrees with Gaigher, Lund and Makuya

(2002) who established that choosing a marriage partner is a serious challenge for persons with albinism and conflicts in albinism families lead fathers to abandon their homes. It further supports Brown and Mankowski (1993) who found that feelings of inadequacy, helplessness and hopelessness lead PWAs to experience anger and emotional withdrawal, causing depression.

The findings on the challenges faced by persons with albinism relate to the resilience theory of Kumpfer (1999) in the sense that stressors or challenges activate the resilience process and create a disequilibrium or disruption in the homeostasis of the individual or organizational unit (e.g. family, group or community). The degree of stress perceived by the individual depends on the perception, cognitive appraisal and interpretation of the stressor as being threatening or aversive. In this study, persons with albinism experienced challenges concerning individuals, families, community and cultures which hindered them in various areas of life, including socially, economically, psychologically, spiritually and health-wise.

The coping strategies adopted by persons with albinism to deal with the challenges that they face included awareness programs, advocacy, support from family and friends, personal development and care, withdrawal from society, counseling, security, networking and acceptance. Organizations such as APAM, DIWA and KAPRA helped the participants to cope with living with their condition as they provided them with information on how to take care of their skin, how to wear protective gear and in terms of the provision of whistles and torches to help them with security. The awareness helped the participants to advocate for themselves and also to confront those who treated them differently.

Also, the participants and their families received psychosocial support through counseling from both the hospital and the organizations that support persons with albinism. This helped the participants to accept their condition and their families to understand the albinism condition well. The skin clinic days at the hospital enabled the participants to meet with others dealing with the same condition. This act promoted networking as they shared ideas and encouraged one another. These findings corroborate those from Braathen and Ingstad's (2006) study, which found that some parents were found to support and love their children. These findings further agree with those of Cruz-Inigo et al (2011) who found that improved security helps persons with albinism to cope and live peacefully.

It was also observed in the current study that some of the participants, both male and female, coped by coloring their hair black to avoid being labeled and sidelined by others. This was in a bid to look similar to their community members whom they thought were sidelining them as a result of the color difference in both their skin and hair. This was also observed in the families and communities who had relatives with a very light skin complexion but black hair, where only persons with albinism had a different hair color.

The findings above on the coping mechanism adopted by persons with albinism are consistent with the resilience theory put forward by Kumpfer (1999). It states that internal self-characteristics including internal individual spiritual, cognitive, social/behavioral, physical and emotional/affective competencies or strengths are needed to be successful in different developmental tasks, cultures and personal environments. Persons with albinism in this study utilized the counseling opportunity for emotional and spiritual support by attending church sessions and engaging in different church activities. This helped them to cope with the numerous challenges that they experienced.

The recommendations made by persons with albinism to improve their lives included the provision of transport money, the formation of clubs, assistance from NGOs, the provision of soft loans and the creation of more awareness targeted at persons with albinism living in rural areas. In the current study, it was observed that relatives and parents of PWA were allowed to collect the sunscreen lotion on behalf of their children or relatives provided they bring their health passport book in missionary hospitals only unlike government hospitals. Government hospital put these measures in place to allow persons with albinism to be screened physically by the dermatologist who may be able to detect any skin related problems and treat it effectively. However, due to lack of money for transport to major hospitals, the health of persons with albinism is compromised and they end up going to hospitals when they are in critical condition. In addition, albinism is a genetic condition and in some instances, some of the families have more than five members with albinism. It was a financial burden for the families to transport all the members to hospital for screening on monthly basis hence their insistence that one member of the family should collect the lotion for the rest of the family members to alleviate their economic burden on transportation. The participants suggested that giving them transport money to go to central hospitals for a medical review and to collect sunscreen lotion could help in the early discovery of skin problems like cancer. In addition, organizations that are interested in working with them should consider including allowances for transport and per diem in their budget, coupled with managing their time for meetings effectively. Persons with albinism were of the view that establishing their own business clubs will be helpful in enabling them to hold meetings, to share ideas and to work in the shade. This will also give them a sense of belonging because currently, most groups do not understand where persons with albinism belong.

The participants also recommended that organizations should be inclusive and that financial institutions should offer them soft loans to establish businesses that will enable them to work in the shade to increase their level of productivity in society. Furthermore, the participants suggested that any awareness programs should be targeted to reach persons with albinism in rural areas to aid in extending their lifespan. These findings confirm those of the studies previously conducted (Cruz-Inigo et al., 2011; Kromberg, Zwane & Jenkins, 1987; Pooe-Monyemore et al., 2012) which found that clinical genetic outreach programs in rural areas assisted parents in the management of albinism through understanding and acceptance, thus removing ignorance and superstitions.

The findings above on the recommended ways to improve the lives of persons with albinism support Kumpfer's (1999) resilience theory where positive outcomes or successful life adaptations in relation to specific developmental tasks are noted to be supportive of later positive adaptations within specific new developmental tasks. This leads to a higher likelihood of reaching the global designation in adulthood as a "resilient child or adult". Thus persons with albinism in this study who bounced back from the challenges that they faced were able to be resilient. Positive outcomes such as success in their academic career, advocating for others and advising their colleagues about albinism were additionally identified.

## CHAPTER 5

### SUMMARY OF THE FINDINGS, CONCLUSIONS AND RECOMMENDATIONS

#### Introduction

This chapter starts with a summary of the key findings of the study which are based on the objectives of the study. The chapter then outlines the conclusions as well as the recommendations of this study. The last part of the chapter suggests areas for further research.

#### 5.1 Summary of the Findings

The study investigated the following objectives: a) to identify the challenges faced by persons with albinism in Lilongwe District, Malawi, b) to find out the coping mechanisms of persons with albinism in Lilongwe District, Malawi and c) to ascertain recommendations from persons with albinism that can be used to improve their living status in Lilongwe District, Malawi.

It was found that persons with albinism face various challenges. Some experienced educational challenges and dropped out of school at the lower primary level because of their inability to see the blackboard or read the textbooks due to the small font size. The study found that the undesirable attitude of their teachers and peers in school, related to bullying and deplorable name-calling, contributed to their poor academic performance. This led the persons with albinism to lose interest in continuing with their education, which is a vital part of their future life when it comes to gaining employment. The education challenges also contributed to their poor financial status which means that they live in abject poverty and are sidelined in the decision-making undertaken in the society.

This study found that persons with albinism, together with their families, lacked general knowledge on the albinism. It was found that they did not know what caused albinism. It was established in this study that more information on awareness and programs on albinism started targeting persons with albinism in 2016 from organizations such as APAM and Tiritonse as a result of the widespread news on the killings of PWA.

Aside from these challenges, it was found that persons with albinism were unable to work effectively outside in the sun. This challenge affects their productivity and leads them to remain socially disadvantaged as they do not have enough resources available compared to pigmented persons. Additionally, it was found that they experienced stigma and discrimination in various ways that affected their social and psychological wellbeing. This makes them feel disappointed, frustrated and angry.

They were also affected emotionally by the demeaning names given to them by their peers and community members as well as the birth names given to them by their parents. Sometimes these names had negative connotations, reflecting how unpleasant it was to have given birth to a child with albinism. The study also found that there was a challenge related to the local terminology where persons with albinism were referred to using descriptive statements. The use of the words ‘persons with albinism’ was found to be appropriate because it puts the individual before the condition unlike the phrase ‘persons living with albinism.’

The study found that persons with albinism and their mothers were isolated by their family members who did not want to share utensils for fear of catching albinism. In churches and communities, people were afraid and not comfortable interacting with them. In addition, due

to the killings in Malawi, persons with albinism feared for their lives and they lost trust both in their family and in their community members who they thought could have selfish interests. It was found that the breaking of the marriage vows especially affected the female participants emotionally. Giving birth to a child with albinism resulted in abandonment, rejection and insults from both spouses and families. This left a huge responsibility on the mothers as they had to take care of their abandoned children alone. Furthermore, the study found visual challenges, hearing problems, the bleeding of the lips, skin conditions, the non-availability of sun screen lotion, the negative attitudes of the health personnel and the long distance to the health facility to be the major health challenges faced by persons with albinism.

Kumpfer's resilience theory (1999) states that the external environmental context includes the balance and interaction of salient risk, protective factors and the processes involved in the individual external environment within the critical domains of influence (i.e. family, community, culture, school and peer groups). These change with age and they are specific to culture, geographic location and historical period. Persons with albinism may fail to cope with the challenges faced due to a lack of support that could otherwise help them to balance between their problems and the solutions available. For instance, if in the early years of life both the individual and the external environment fail to understand albinism, then demeaning names, stigma, discrimination and rejection are more likely to develop.

Furthermore, the study found that the coping strategies that persons with albinism have adopted to deal with the challenges they face include awareness programs, advocacy, support from their family and friends, personal development and care, withdrawal, counseling, security, networking and acceptance. These coping strategies helped some of them to accept

their condition and they also helped their families understand albinism as well. It also opened up links for socialization with other individuals with the albinism condition and allowed them to share their experiences. The findings above on the coping mechanisms adopted by persons with albinism are consistent with the resilience theory by Kumpfer (1999). This theory states that internal self-characteristics that include internal, individual, spiritual, cognitive, social/behavioral, physical and emotional/affective competencies or strengths are needed to be successful in different developmental tasks, cultures and personal environments. Persons with albinism also have the internal strength and desire to cope with the challenges around them if they are given external support. Socially, persons with albinism interact with, encourage and get support from one another and also from NGOs.

Finally, this study found that the recommendations made by persons with albinism included the provision of transport money by their parents to enable them to go to central hospitals for a medical review and to collect sunscreen lotion. Attending hospital appointments could help in the early discovery of skin conditions and the formation of clubs to enable the sharing of ideas to promote entrepreneurship to improve their productivity. NGOs can assist by advocating for them and including them in their operations. Financial institutions can consider providing soft loans for the purpose of entrepreneurship. Lastly, awareness programs can be used to reach other persons with albinism living in rural areas so then their lives can be improved.

## **5.2 Conclusions**

The findings of this study show that the education challenges faced by persons with albinism are because of a lack of conducive learning environments in schools. The attitudes of their peers, teachers and family have also made them drop out of school. As a result of a lack of understanding of albinism by both their family and the persons with albinism, there is an

increased vulnerability in relation to their health because they are not able to access the required medical attention in time.

As shown in the findings of this study, persons with albinism cannot afford to meet their health needs because of travel distance from rural areas to the central hospitals that provide sunscreen lotion, zinc and a review of their skin condition. Persons with albinism have to work against the sun and this limits their productivity.

Furthermore, the study findings revealed that persons with albinism are able to cope with the challenges they face. Awareness programs conducted by NGOs have played a role in teaching them how to take care of themselves in terms of their condition and how to accept themselves. Though others have coped by withdrawing, it helped them to heal from their emotions and to bounce back well. Persons with albinism get support from their family and friends through networking, counseling and the provision of security.

It can therefore be concluded that the recommendations suggested by persons with albinism including the formation of clubs, access to soft loans, the provision of transport money to go to hospital and awareness programs could be sustainable if applied. These suggestions are what they feel can help them to improve their livelihood.

### **5.3 Recommendations**

This study provides useful insights into the challenges faced by persons with albinism and how they cope with their condition. Based on the findings in this study, the following recommendations can be made.

This study shows that most of the participants experienced challenges in relation to their education. Therefore, it is recommended that governments should provide conducive learning environments for persons with albinism. This may include classrooms with good lighting, learning under shade in classrooms, the provision of large print text books and extra support from the teachers in areas that the PWA do not understand. Governments should introduce lessons and a curriculum framework on the different gene defects and equal rights from lower primary school onwards to enable young learners to understand the different health concerns and conditions involved. The Government of Malawi should consider introducing special adult literacy classes for persons with albinism to enable them to learn how to read and write. Vocational training centers should be allowed to teach them practical hands-on skills, irrespective of their academic qualifications. This is important because persons with albinism should be able to read and write, which will add extra knowledge to their daily lives.

Different stakeholders working with persons with albinism should explain the issues concerning albinism in simple terms. This is because despite the level of awareness that NGOs have been raising in rural communities, communication remains a barrier as most persons with albinism do not understand their condition.

Persons with albinism are economically disadvantaged, therefore it is recommended for the government to include them under the groups that are supported by affirmative actions when job vacancies arise. The lack of transport money to access medical care can be managed if the Ministry of Health collaborates with the local skin and eye department to conduct joint mobile clinic services in rural areas. This can be done in liaison with health surveillance assistants (HSAs) based in the community. It is further recommended for the government to deploy dermatologists and optometrists to rural hospitals where most persons with albinism live.

It is recommended by this study to find out if there is a consensus from persons with albinism to let society know of the rightful and befitting term to call them. The study recommends that financial institutions in Malawi should consider giving soft loans to persons with albinism. This should come with business training and financial management.

#### **5.4 Implications for Social Work Practice**

Social workers should develop an understanding of the different types of gene defect in the lives of people in the community and how to handle them effectively by reading and conducting research. For instance, the social worker should advocate for early morning or late afternoon meetings and training when such activities include persons with albinism. This is as the sun limits their productivity and it is also a health hazard to their lives.

Social workers have various roles to play in society such as advocates, brokers, empowers and educators. Marginalized populations, such as persons with albinism, are normally voiceless and they need an advocate to speak on their behalf. Social workers as advocates can work together with community agents of change, education workers and healthcare workers to stand up for persons with albinism to ensure that they get access to proper medical care and conducive learning environments in order to promote productivity. This could be addressed by informing the local leaders of the need to request development funding from the local parliamentary member to be used in this needy area. In addition, the challenges should be presented in parliament by the approached member of parliament in order to seek further assistance. The study identified there to be a lack of adequate knowledge on the cause of albinism. Based on this finding, it is recommended that social workers as educators should conduct on sensitization programs whereby both persons with albinism and the wider community members are educated on the condition of albinism.

It is clear from this study that some of the participants experienced shame, fear, stigma and discrimination which led them to cope by isolating themselves and withdrawing from community activities. Social workers should conduct counseling and further connect such people to psychologists to help them rebuild themselves. In addition, social worker should encourage persons with albinism to attend meetings at a skin clinic and APAM meetings for the purpose of socialization and support.

There is a crucial need for research in this area to be conducted by social workers. Persons with albinism face discrimination and vulnerability in most areas of their lives. The professional values of the social work profession and its commitment to social justice places social workers in an ideal position to provide advocacy, lobbying, educational campaigns and upholding the rights of persons with albinism. There is a need for social workers to conduct further research on persons with albinism in different geographical areas.

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**Appendix 1: Interview Guide for Participants (English and Chichewa language)**

**Understanding the living experiences of persons with albinism in Malawi**

My name is Thandiwe Tambala Kaliati an Mphil student of University of Ghana, Social Work Department. This study seeks to gather information about the living experiences of persons with albinism in Lilongwe district. The information could assist the government and other NGOs to develop policies and intervention strategies that can solve the social challenges faced by person with albinism in the country. Thank you very much for your co-operation.

*Ine Thandiwe Tambala Kaliati ndine wophunzira waku University of Ghana, kumalo komwe amaphunzitsa ukadaulo wothandiza kukhala bwino kwa anthu mamdera. Ine ndiri pakafukufuku mu Lilongwe wokhuza mavuto muchikhalidwe chaanthu achialibino malingana ndimmene adabadwira, amakhala bwanji mu moyo wawo watsiku ndi tsiku ndipo Kafukufuku ameneyu athandiza kuunikira oyendetsa ntchito zaulangizi waanthu mmadera, boma ndi anthu omwe adabadwa ndi alibino ndi ena onse kupeza dongosololo moyenera kulitsata kuti ntchito yawoyo ikathe kuthandiza bwino anthu ena.*

**a. Demographic information /Mawanga a ofunsidwa mu kafukufuku.**

1. Could you please tell me about yourself, (Age, where do you come from, place of birth).

*Mungandifotokozere tsatane tsatane mbiri yanu. (zaka zanu zobadwa, komwe munabadwira komwe mumachokera.*

2. Could you please tell me about your parents, (probe on if they have albinism or not)?

*Mungandilongosolere bwinobwino zamakoloanu. (kufunitsitsa kudziwa ngati anabadwa ndi alibino).*

3. Are your parents staying together? If not what was the cause of the separation?

*Ndingofuna nditadziwa ngati makolo anu ali limodzi? Ngati Sali limodzi chinawalekanitsa ndi chani ngati mukudziwa.*

4. Do you have any history of albinism in your clan?

*Kumtundu kwanu kuli mbiri ya achialibino ngati?*

5. How many siblings do you have?

*Munabandwa anthu angati mubanja mwanu?*

6. How many of your siblings have albinism? What is their sex? (Probe: female how many and male how many)?

*Ndiabale anu angati omwe anabadwa ndi alibino? Ndiwati? (akazi kapena amphongo ndi angati)?*

7. What is your marital status?

*Muli pa banja kapena ayi?*

8. Are you married to a person with albinism or not? And what made you marry a pigmented woman or woman with albinism?

*Ngati munakwatiwa, munakwatiwa kapena kukwatidwa ndi bambo kapena mayi wachi alibino? Chinakupangitsani kusankha motero chinali chani?*

9. How many children do you have?

*Muli ndi ana angati?*

10. How many children were born with albinism and their sex?

*Mwa anawo ndi angati anabadwa ali ma alibino?*

11. How many children were born without albinism and their sex?

*Ndipo ndi angati anabadwa opanda chialibino ndipo iwowa ndii amuna kapema a kazi?*

**b. Individual challenges faced by person with albinism.**

1. Could you please share your experience as a person with albinism?

*Tandilongosolerani mmene munakulira pokkhala munthu wa alibino?*

2. What do you think albinism is

*Kodi mukamamva kuti alibino inu mumati ndi chani?*

3. What is/are the cause/s of this condition?

*Kaya mumadziwa chiri chonse chomwe chimapangitsa munthu kukhala wa alibino?*

4. Where did you learn of your condition? From who?

*Kodi zachialibino munaphunzirira kuti? Ndipo kuchokera kwa ndani?*

5. How do you feel about being a person with albinism?

*Mumamva bwanji kukhala munthu wachi alibino?*

6. How does albinism affect your life? (probe)

*Ndipo zimakukhudzani bwanji mumoyo wanu? (kufunsinsinsa)*

7. Could you please tell me the social challenges that you face in your daily life? (Probe e.g. health, education, social, stigma and physical)?

*Ndimavuto anji omwe mumakumana nawo pamoyo wanu wa tsiku ndi tsiku (mu umoyo, mmaphunziro, chikhalidwe, kusalidwa ndi mthupi)?*

8. Do you experience any health, related challenges?

*Muli ndi mavuto ena aliwonse okhudzana ndi zaumoyo wanu? Ndipo ndi mavuto anji?*

**c. Family challenges faced by person with albinism**

1. How does your family understand your condition?

*Banja lanu limamvetsetsa bwanji za alibino?*

2. How do they treat you in your family compared to your brothers and sisters without albinism

*Ku banja kwanu mumakhalitsana bwanji ndiazibale anu kutengera kuti inu ndi achilibino?*

3. Could you describe the challenges the family faces as a result of your albinism?

*Mungandilongosolere mavuto omwe mumakumana nao kubanja kwanu?*

**d. Community challenges faced by person with albinism**

1. Could you please tell me any social activities that you are involved in your community?

What are the activities?

*Mumatenga nao magawo otani mudera mwanu?*

- 5.0 Do you experience any limitations with any of the social activities in your communities?

What are the limitations?

*Pamakhala zoletsa ziri zones ngati potenga nao mbali muzochitika kumadera anu? Ngati ziripo ndizichani?*

- 6.0 Are you included in any leadership position in the community?

*Mumaikidwa nao mumautsogoleri mu zochitika mmidzi mwanu?*

- 7.0 Could you explain your attachment to your community and how do people in your community treat you??

*Mumakhalitsana bwanji ndi anthu aku midzi yanu?*

- 8.0 What are the reactions of strangers towards your condition in your community and other communities?

*Alendo obwera mmidzi yanu amakuona bwanji?*

**e. Society challenges faced by person with albinism**

1. What are the challenges that you experience from government, non -governmental organizations and institutions with regard to your condition?

*Mavuto anji mumakumana nao kuchokera ku boma, mabungwe osiyana siyana kutengera mmene munabadwira?*

2. How is your social life being affected with/out their intervention?

*Moyo wanu umakhuzika bwanji ndizochitika ngati zimenezi?*

3. Are there any employment opportunities for you in the society? (Probe –what are the limitations)?

*Kodi mwai wa ntchito umapezeka? (ngati ai mavuto omwe mumakumana nao ndi ati)?*

4. What kind of work do you do and why?

*Ntchito zomwe mumagwira ndi zamtundu wanji?*

5. What kind of job will be suitable for you?

*Ndintchito zANJI zomwe mumaona zimakuyanjanani?*

6. Do you belong to any group in your community? (Probe – what is the name of the group, how do you join, what do they do)?

*Munalowa nao mugulu lina liri lonse kudera kwanuko? (dzina la guru ndi chani ndipo zokuyenerezani kulowa nao ndi chani ndipo mumapanga chani ku guruko)?*

7. What are the challenges you face in joining community groups?

*Alipo mavuro ngati omwe munakumana nao polowa maguluwa?*

8. Could you describe to me how the awareness and advocacy strategies have impacted your life?

*Kodi zidziwitso za alibino zakuthandizani motani kapeni ai?*

**f. Cultural challenges faced by person with albinism**

1. What form of stigma and discrimination do you face in your life?

*Mumasalidwa munjira zotani mu moyo wanu?*

2. Do you know any myths about the causes of albinism?

*Mumadziwako zikhulupiriro zina ziri zonse zokhudzana ndi chomwe chipamgitsa munthu kukhala wa alibino?*

3. Do you experience any cultural challenges in your life?

*Mumakumana ndi mavuto achikhalidwe ndi dzikhulupiriro za makolo?*

4. Have you ever been attacked or abused?

*Munakumanako ndi nkhaza zina ziri zonse pa moyo wanu?*

**g. Coping mechanism adopted by persons with albinism**

1. How do you cope with the challenges you face with your condition, health, education, physical, social and family?

*Mumathana bwanji ndi mavuto omwe mumakumana nao chifukwa cha thupi lanu mu umoyo, maphunziro, thupi, chikhalidwe and banja lanu?*

2. How do your family, community, society and culture cope with your condition?

*Banja lanu, dera lanu, mzinda wanu andi chikhalidwe chanu amakwanitsa bwanji pokhalirana limodzi ndi anthu achialibino?*

3. How do you cope yourself with your condition?

*Mumazipansa chisamaliro chanji panokha?*

4. What type of support do you receive from your family/community/society and culture practices?

*Abale, mudzi ndi chikhalidwe chokuzungulirani chimakupatsani chithandizo chotani pokhudzan andi kubadwa kwanu ndi chialibino?*

5. What challenges do you face in getting the support?

*Ndimavuto anji omwe mumakumana ano pofuna thandizo?*

6. What change has the support received brought into your life (Positive or negative)?

*Mathandizo omwe mukulandira akupindurirani chani?*

7. How do you access the needed support?

*Mumapeza bwanji thandizo lofunika?*

8. What type of support do you require? (Probe - From where and by who)

*Koma inu mumafuna thandizo lanji ( kuchokera kuti ndipo ndi ndani)?*

9. What cultural changes would you like to hear? (Probe – how can it be done?)

*Zikhalidwe ndi zikhulupiriro zANJI zomwe mumafuna mutanza zitatha?*

#### **k. Recommendations**

1. Do you have any recommendation with regard to your conditions?

*Mungandiuze malangizo omwe mumafunira anthu kapena mabungwe angamakugwirireni bwino kutengera mmene munabadwira ndi alibino?*

2. Where the recommendation should be addressed to?

*Malangizo amenewa apite kwa ndani?*

Thank you!

**Appendix 1a: Interview Guide for the Key Informants (English and Chichewa language)**

**Understanding the living experiences of persons with albinism in Malawi**

My name is Thandiwe Tambala Kaliati, an MPhil student of University of Ghana, Social Work Department. This study seeks to gather information about the living experiences of persons with albinism in Lilongwe District. The information could assist the government and other NGOs to develop policies and intervention strategies that can solve the social challenges faced by person with albinism in the country. Thank you very much for your co-operation.

*Ine Thandiwe Tambala Kaliati ndine wophunzira waku University of Ghana, kumalo komwe amaphunzitsa ukadaulo wothandiza kukhala bwino kwa anthu mamdera. Ine ndiri pakafukufuku mu Lilongwe wokhuza mavuto muchikhalidwe chaanthu achialibino malingana ndimmene adabadwira, amakhala bwanji mu moyo wawo watsiku ndi tsiku ndipo Kafukufuku ameneyu athandiza kuunikira oyendetsa ntchito zaulangizi waanthu mmadera, boma ndi anthu omwe adabadwa ndi alibino ndi ena onse kupeza dongosololo moyenera kulitsata kuti ntchito yawoyo ikathe kuthandiza bwino anthu ena.*

-----

1. Could you please share your experience working with person with albinism?

*Mungandilongosolereko zomwe mumakumana nazo pogwira ntchito ndi anthu a chilibino?*

2. Do you think persons with albinism understand their condition and its causes?

*Mukukhala nao anthu achialibino, mumaona ngati amamvetsetsa za momwe anabadwira? Ngati samvetsatsa mukoona kuti chingakhale chani chomwe chimapangitsa?*

3. What are the social challenges do you think they experience in their daily life? (Probe e.g. health, education, social, stigma and physical)?

*Mukuona kwanu amakumana ndi mavuto anji? (mu umoyo wawo, maphunziro, chikhalidwe, kusalidwa ndi pathupi pao)?*

4. Do you think their families understand albinism condition?

*Mumaona ngati ku mabanja awo azibale ao amamvetsetsa ualibino?*

5. Could you please tell me any social activities that you are involved in with persons with albinism?

*Mumagwirana nao ntchito zANJI anthu achialibinowa?*

6. What are the challenges that you experience from government, non-governmental organizations and institutions in working with persons with albinism?

*Mumakumana ndi mavuto anji pogwira ntchito ndi anthu achialibino kuchokera ku boma, mabungwe osiyana siyana?*

7. What kind of support do you offer persons with albinism to cope with the challenges they face?

*Mumawathandiza bwanji anthu achialibino kuti athane ndi mavuto omwe amakuna nao?*

8. How do persons with albinism access the needed support?

*Thandizoli mumalipeza kuti?*

3. Do you have any recommendation that will improve the lives of persons with albinism?

*Upangiri wanu pofuna kukonza njira zokonza umoyo wabwino wa anthu achialibino  
ungakhale otani?*

Thank you!

**Appendix 2: Letter of approval from the University of Ghana**



**UNIVERSITY OF GHANA**  
ETHICS COMMITTEE FOR THE HUMANITIES (ECH)

P. O. Box LG 74, Legon, Accra, Ghana

My Ref. No.....

15<sup>th</sup> December, 2017

Ms. Thandiwe Tambala-Kaliati  
Department of Social Work  
University of Ghana  
Legon

Dear Ms. Tambala-Kaliati,

**ECH 071/17-18: EXPERIENCES OF PERSONS WITH ALBINISM IN LILONGWE, MALAWI**

This is to advise you that the above reference study has been presented to the Ethics Committee for the Humanities for a full board review and the following actions taken subject to the conditions and explanation provided below:

Expiry Date: 12/06/18  
On Agenda for: Initial Submission  
Date of Submission: 13/11/17  
ECH Action: Approved  
Reporting: Quarterly



Please accept my congratulations.

Yours Sincerely,

Rev. Prof. J. O. Y. Mante  
ECH Chair

CC: Prof. Mavis Dako-Gyeke, Department of Social Work, University of Ghana.

**Appendix 3: Letter of approval from Malawi Ethics committee**



**REF.NO.NCST/RTT/2/6**

**9th March, 2018**

C/O Volta River Aviation  
PMB CT 216  
Cantonments  
Accra  
Ghana

Dear Thandiwe Tambala-Kaliati,

**RESEARCH ETHICS AND REGULATORY APPROVAL AND PERMIT FOR  
PROTOCOL NO. P.01/18/243: LIVED EXPERIENCES OF PERSONS WITH  
ALBINISM IN LILONGWE DISTRICT, MALAWI**

I am pleased to inform you that the above referred research study has officially been approved. You may now proceed with its implementation. Should there be any amendments to the approved protocol in the course of implementing it, you shall be required to seek approval of such amendments before implementation of the same.

This approval is valid for one year from the date of issuance of this letter. If the study goes beyond one year, an annual approval for continuation shall be required to be sought from the National Committee on Research Ethics in the Social Sciences and Humanities (NCRSH) in a format that is available at the Secretariat. Once the study is finalized, you are required to furnish the Committee and the Commission with a final report of the study. The committee reserves the right to carry out compliance inspection of this approved protocol at any time as may be deemed by it. As such, you are expected to properly maintain all study documents including consent forms.

Wishing you a successful implementation of your study.

Yours Sincerely,

Mike Kachedwa  
HEAD OF NCRSH SECRETARIAT

**For: CHAIRMAN OF NCRSH**

#### **Appendix 4: Participant Information Sheet**

##### **Living experiences of persons with albinism in Lilongwe – Malawi**

Dear Participant,

I am Thandiwe Tambala-Kaliati, a Masters student at the University of Ghana in the Faculty of Social Sciences, Department of Social Work. I intend to undertake a research project on the above subject in fulfillment of an MPhil in Social Work.

I am conducting this study to learn about the social challenges, coping strategies and support systems available for persons with albinism. The study will be conducted in Lilongwe, Malawi.

You have been chosen by chance to participate in the study. I want to assure you that all of your answers will be kept strictly secret. I will not keep a record of your name or address. You have the right to stop the interview at any time, or to skip any questions that you don't want to answer. There are no right or wrong answers. Some of the topics may be difficult to discuss, but other persons with albinism have found it useful to have the opportunity to talk.

You may not directly benefit from the study. Your participation is completely voluntary but your experiences could be very helpful to other persons with albinism in Malawi. You qualify for participation if you are aged eighteen or more and you have albinism. You will be interviewed for a period of about 45 minutes to one hour and in case of focus group discussion the interviews may take up to 2hours and 30 minutes. You may withdraw from the study at any point without penalty. All information collected is confidential and will be used

for research purposes only. In addition, data collected will be anonymous. At the end, a hat as a token of thanks/appreciation will be given to the respondents.

**Note:**

If you have any questions regarding your rights and welfare as a research participant, please contact the following person:

**The Chairperson**

**National Commission for Science and Technology**

**Lingadzi House, City Centre**

**Private Bag B303**

**LILONGWE 3**

**Malawi**

Telephone: 002651771 550

Fax: 002651772 431

Email: [directorgeneral@ncst.mw](mailto:directorgeneral@ncst.mw)

Website: [www.ncst.mw](http://www.ncst.mw)

Thank you for your assistance.

**Thandiwe Tambala- Kaliati**

**Appendix 4a: Kalata Yomudziwitsa Munthu Wotenga Mbali za Kafukufukuyi**

Okondeka,

Ine ndine Thandiwe Tambala Kaliati ndipo ndili pakafukufuku wokhuza mavuto muchikhalidwe chaanthu achialibino malingana ndimmene adabadwira, amakhala bwanji mu moyo wawo watsiku ndi tsiku ndipo ndi chithandizo chanji chomwe amapeza pamoyo wao watsiku ndi tsiku.

Kafukufuku ameneyu athandiza kuunikira oyendetsa ntchito zaulangizi waanthu mmadera, boma ndi anthu omwe adabadwa ndi alibino ndiena onse kupeza dongosolo loyenera kulitsata kuti ntchito yawoyo ikathe kuthandiza bwino anthu ena.

Kutenga nawo mbali mukafukufuku ameneyu ndi kofunika kwambiri chifukwa zitithandiza kudziwa zambiri pa mutu umenewu. Ndinu oyenera kutenga nawo mbali ngati munabadwa ndi alibino, zaka zakubadwa kuyambira khumi ndizisanu ndi zitatu (18) kupitilira. Mufunsidwa mafunso kwa pafupifupi mphindi makumi anayi ndi zisanu (45) kufika ola limodzi. Ngati mukutenga nao mbali mu zokambirana zagulu nthawi yokambirana itha kuchulukirapo kufika mawora awiri ndi makumi atatu malingana ndi momwe zokambirana zikuyendera.

Kutenga mbali kwanu mukafukufukuyi nkosakakamizidwa. Muli ndi ufulu kukana kapenanso kusiyira pakati kafukufuku asanathe ndipo simuzalandira chilango chillichonse. Zokambirana zonse zidasungidwa mwachinsinsi komanso zidzagwira ntchito yakafukufukuyi basi. Poonjezera apo zomwe mudzafotokoze zidasungidwa popanda kudziwa dzina lanu.

Zokambirana zathu zidzakhudza mafunso ena amene mwina mungakhale omangika kuyankha kapena osasangalala nawo chifukwa ndi mafunso omwe akukhudzaza nkhanza ndi zipsinjo zomwe munadutsamo. Anthu omwe anabadwa ndi alibino ambiri anachiona chofuni kakukamba zankhaniyi. Koma ngati mukuona kuti mafunso oterewa anga kukhumudwitseni, muli omasuka kukana ngati mumatenganawo mbali m'kafukufukuyi. Komanso mulindi ufulu kufunsa mafunso ena alionse okhudza kafukufukuyi. Pakutha pazonse, otenga nawo gawo mukafukufukuyi sadzathokozedwa ndi china chirichonse.

Ngati muli ndi mafunso komanso madandaulo okhudza ufulu wanu mukafukufukuyi, mutha kufunsa woyang'anira zaufulu waotenga mbali mu kafukufuku pa Keyalayi:

**The Chairperson**

**National Commission for Science and Technology**

**Lingadzi House, City Centre**

**Private Bag B303**

**LILONGWE 3**

**Malawi**

Telephone: 002651771 **550**

**Fax: 002651772 431**

**Email: [directorgeneral@ncst.mw](mailto:directorgeneral@ncst.mw)**

**Website: [www.ncst.mw](http://www.ncst.mw)**

Zikomo kwambiri chifukwa chotithandiza.

**Thandiwe Tambala- Kaliati**

### **Appendix 5: Informed Consent for Participation in the Study**

This study seeks to learn about the social challenges, coping strategies and support systems available for persons with albinism. The study will be conducted in Lilongwe, Malawi. As stated in the invitation to participate letter, the study may remind you of some horrible situations you went through, which may bring distress, embarrassment and some kind of panic; please feel free to explain and you will be assisted accordingly. The main potential benefits of the study are that it will contribute to knowledge on the topic and the knowledge gained may also help in designing effective programmes aiming at helping persons with albinism in their social life. No costs or payments are associated with participating in the study.

#### **Based on the information provided regarding the research project, I understand that:**

1. The time required for the interview is about forty-five minutes to one hour.
2. My participation is entirely voluntary and I may terminate my involvement at any time without penalty.
3. All my data are confidential and the data will be destroyed within five years after completion of the study.
4. All data are for research purposes only.
5. If I have questions about the research, or if I would like to see a copy of the final findings of the study, I can contact the researcher by calling him on the number given or write to him on the address given.

I \_\_\_\_\_ voluntarily **agree** or **disagree** to participate in this study \*(Please select the appropriate option by circling or ticking)\*.

Date: \_\_\_\_\_ Witness signature \*(if participant is unable to write)\*: \_\_\_\_\_ Date: \_\_\_\_\_

Signature of investigator: \_\_\_\_\_ Date: \_\_\_\_\_

Further information is available from

**Name of investigator:** Thandiwe Tambala- Kaliati

Address: University of Ghana, P O Box LG419, Legon, Accra, Ghana. Phone:  
00233266824860

**Name of Supervisor:** Dr. K Frimpong-Manso. (Senior Lecturer)

Address: University of Ghana, P O Box LG 419, Legon, Accra, Ghana.

Phone: 00233243908246

**Appendix 5a: Kuvomereza Kutenga Nawo Mbali M'kafukufuku**

Monga ndamvera mukalata yomwe ndawerenga /mwandiwerengera ija, ndamvetsetsa kuti Kafukufukuyi ndi wofuna kudziwa mavuto wokhuza m'chikhalidwe cha anthu a chi alibino malingana ndi mmene adabadwira, amakhala bwanji mu moyo wawo watsiku ndi tsiku ndipo ndi chithandizo chanji chomwe amapeza pamoyo wao watsiku ndi tsiku.

Kafukufuku ameneyu athandiza kuunikira oyendetsa ntchito zaulangizi WA anthu am'madera, boma ndi anthu omwe adabadwa ndi alibino ndi ena onse kupeza dongosolo lomwe ayenera kulitsata kuti ntchito yawo yo ikathe kuthandiza bwino anthu ena.

Kafukufukuyi atha kukukumbutsani zina zosasangalatsa zomwe zinakuchitikirani, chonde masukani kunena kuti muthandizidwe moyenera. Palibe choti mupereke potenga nawo gawo mukafukufukuyi.

**Malinga ndi zina zomwe ndawerenga/ mwandiwerengera, ndamvetsetsa kuti:-**

1. Kukambirana kwathu nkwamphindi makumi anayi ndi asanu kufika ola limodzi;
2. Kutenga mbali kwanga nkosaumirizidwa ndipo ndingathe kusiya nthawi ina iliyonse yomwe ine ndafuna;
3. Zokambirana zizasungidwa chinsinsi ndipo zidzaonongedwa pakatha zakazisanu.
4. Zokambirana zidzagwiritsidwa ntchito pakafukufuku yekhayu basi;
5. Ngati pali funso nditha kufunsa nthawi ina ili yonse pogwiritsa ntchito nambala yalamya kapena keyala zomwe zaperekedwa.

Choncho Ine \_\_\_\_\_ mwaufuluwangandavomera / **ndakana**  
kutenga nawo mbali mu kafukufuku ameneyu.\*(Chonde zunguzani kapena chongani  
yankho loyenera)\*.

*Tsiku Lofunsidwa:* \_\_\_\_\_

*Mboni\*(ngati otenga mbali sangathe kulemba) :* \_\_\_\_\_

*Tsiku* \_\_\_\_\_

*Dzina la Wofufuza:* \_\_\_\_\_

*Tsiku Lofunsa:* \_\_\_\_\_

Ngati mutafuna kudziwazina, funsani anthu awa

Mwini wakafukufuku: Thandiwe Tambala-Kaliati

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