

Life Experiences of People with Albinism in Gaborone, Botswana

Formatted: Right

ABSTRACT

It has been observed that, despite the efforts by various stakeholders to raise awareness on oculocutaneous albinism and research around the issue globally, regionally, and nationally, stigma and marginalization plague many communities in Botswana. The study explores the life experiences of people with albinism. It draws from the direct testimony of people with albinism. In addition, the study contributes to existing knowledge on a visible disability more than its physical and mental limitations. Thus, it promotes awareness of what appearance means cross-culturally and suggest ways in which the situation could be addressed and enhanced. Key words: Albinism, stigma, marginalization

Formatted: Font: Not Italic

1. INTRODUCTION

The study explores the life experiences of people with albinism in Gaborone, Botswana and the misconceptions of societies towards such people. Derived from the Latin word 'albus' meaning 'white', oculocutaneous albinism (OCA) is a relatively rare genetic disorder in which the body does not biosynthesize melanin [1]. Melanin is a photo protective protein whose role in the skin is to absorb ultraviolet (UV) light and prevent damage. Without melanin the skin is more prone to sunburn and skin cancer [1]. In addition, lack of melanin results in a triad of signs which is pale skin, light hair, and pale iris colour. The condition is inherited in an autosomal recessive manner, which implies that the person with oculocutaneous albinism inherits two faulty genes, one from each parent. Both parents of a person with oculocutaneous albinism may appear unaffected but carry one faulty and one normal gene each [2,3].

Formatted: Font: Italic, Highlight

Formatted: Indent: First line: 0"

Formatted: Font: Italic

Formatted: Indent: First line: 0"

Owing to the absence (or minimal production) of melanin, people with oculocutaneous albinism are affected by a variety of physical and physiological conditions, including marked sensitivity of the skin and increased risk of skin cancer caused by over-exposure to the sun. In addition, persons with oculocutaneous albinism may present with abnormal development of the optic nerve, which might result in poor vision [2,3]. Although the person with oculocutaneous albinism must cope with biological threats, literature reveals that the major challenge faced by people with such a condition in most societies, is stigma and prejudice from myths, superstition, and misinformation [2, 3].

Furthermore, [4] emphasizes that stigma and discrimination have a significant impact on the self-image and self-respect of the individual concerned. This triggered the interest of the researchers to explore the experiences of people with oculocutaneous albinism in Gaborone, Botswana.

1.1 Statement of the Problem

A study by [1] revealed that in the UK (United Kingdom), OCA is estimated to affect 3716 individuals (1 in 17 000 people) while the total population of individuals with OCA in Africa is unknown, and its incidence varies between countries and within regions [1]. In Tanzania, the OCA population is estimated at 31 345 (1 in 1429 people), which is 8.5 times the UK OCA population. Zimbabwe has an OCA population like that of the UK, estimated at 3050 (1 in 4000–5000 people), but its total population is a quarter of that of the UK. In South Africa's Venda region, the incidence is 1 in 1970 (Lund. Two clans with the same number of individuals with OCA have an incidence of 1 in 825 people in the Vhatavhatsindi clan and 1 in 3107 people in the Vhalaudzi clan [1]).

According to [3] oculocutaneous albinism is found globally but with a high prevalence in sub-Saharan Africa and in South America. The condition is a global challenge requiring practical and comprehensive intervention [5]. In addition, some studies on oculocutaneous albinism are not current, although their findings are significant for this study. For example, [6] research on oculocutaneous albinism in South Africa between 1982 and 1999, recorded a prevalence rate of approximately 1 in 3 900 in Johannesburg, compared with 1 in 9 635 in Norway and Sweden (average number for both). The South African prevalence rate is higher than in other parts of Africa, such as Nigeria, where it has been reported to be 1 in 5 000 [7]. [8] drawing on the work of [7] focuses on the high prevalence of albinism among the Southern Sotho peoples of whom the Tswana (many people in Botswana) are a part. In this group, the prevalence is 1 in 2254, which is much higher than other comparable Southern African Bantu groups (for example, 1 in 4000 among the Xhosa, 1 in 9700 among the Pedi, and 1 in 28614 among the Shangaan) [8].

However, literature on albinism in Botswana shows that almost no attention has been paid to the coping styles of those affected. Furthermore, there is less research in the field of albinism. Thus, the aim of the study is to explore in-depth knowledge of experiences of people with albinism. It draws from the direct testimony of people with albinism. In addition, the study contributes to existing knowledge on a disability that is more visible on the surface than its physical and mental limitations. Thus, it may contribute to awareness of what appearance means cross culturally and suggest ways in which the situation may be addressed and enhanced.

2. LITERATURE REVIEW

Formatted: Indent: First line: 0"

Albinism is a physical state, but its effects are as much a result of social reactions to the condition as they are of the state itself. In Tswana traditional life there are many different customs and beliefs surrounding the causes and social treatment of people with albinism. [9] states that, in most communities across the world, albinism is not clearly comprehended. However, this is amplified in sub-Saharan Africa largely because the light skin tone of PWAs (persons with albinism) stands out sharply in communities whose members are dark. In some parts of sub-Saharan Africa, the condition was traditionally thought of as a curse' or as a form of 'punishment' from the gods or the ancestors for some wrongdoing of the parents. In other communities, it was thought that there was something wrong with the mother. For centuries, children born with albinism were routinely killed immediately after birth by parents and midwives, and myths about albinism continue to persist in many parts of the continent [9].

Furthermore, there is evidence that people with albinism have negative experiences with members of their communities. Different scholars state that these include: prejudice, stigma based on superstition, myths, labeling, negative attitudes, fear of contagion, teasing, and being stared at.[9] states that persons with albinism experience and continue to suffer stigma, prejudice, stereotyping, and discrimination in sub-Saharan Africa. It is a condition that cannot be hidden and, when a person with albinism is in a group of dark-skinned people, he/she stands out as different. They are a visible minority and, in many parts of Africa, are subject to open discrimination. The author observes that many women have experienced divorce and are shunned by their families after giving birth to children with albinism. They have been accused of sleeping with men of other races, of being cursed and unclean, and of being witches. In addition, children with albinism have also been hidden from the public, forbidden from socializing with others, and treated as outcasts.

In line with previous studies in Limpopo province (South Africa) by [10, 11,12]community stigma and prejudice communityare major challenges of most people with oculocutaneous albinism. The individuals felt socially stigmatised based on their skin colour, which is obvious owing to a lack of pigmentation. According to [13], stigma is associated with a deviation from what is normally expected. Nevertheless, [11] argue that the problems experienced by persons with oculocutaneous albinism do not necessarily relate to their obvious physical difference in terms of skin colour but to the social environment with which they have to cope, which is also clouded by communal myths and superstitions.

[14]in her paper Sociological Studies of People of Color with Albinism (1998) states that there is stigma attached to albinism and that, in general, it is equated to, and categorised as, a blemish, mark, stain, and even disfigurement. It is a visual stigma causing society to view it with suspicion and fear. Unlike any other stigma, albinism is the only condition mistaken for mixed race. People with albinism are also perceived to be less capable or having a character flaw. In Small's study, respondents stated

that the community basically finds reasons to criticise and reject them. A study by [15] on people with albinism in Nigeria, concluded that they suffer socially and psychologically due to family and society's negative attitudes.

The study by [5] found that myths and superstitions about oculocutaneous albinism affected the participants' everyday social life and self-image. The concern was about the most common myth about people with oculocutaneous albinism that they "do not die naturally but simply disappear or vanish".

Kromberg [10] found the myth to be common amongst the South African black population and suggests that it may be based on the distant past when people with oculocutaneous albinism were believed to be the offspring of a woman and a water spirit. The author is also of the opinion that a practical explanation for this myth could be that many people may not have seen individuals with oculocutaneous albinism pass on or die. [16] point out that beliefs in society affect people's attitudes to life, as well as behaviour in religious, ethical, political, and social spheres. [9] argues that, due to misconceptions and myths, persons with albinism in many parts of Africa suffer from stigma and discrimination from birth and day-to-day lives, thus **disregard their** fundamental human rights and basic freedoms.

Myths associated with albinism in South Africa and Zimbabwe have a profound influence on the lives of people with the condition, from birth until death. The beliefs and superstitions surrounding the condition affect family life and interfere with access to education, employment, and marriage [17]. A woman with albinism in Zimbabwe commented, 'People think albinism is caused **because the woman sexual contact with a tokolosh**' [17]. **The authors explained that the tokolosh is a malevolent spirit in Shona folklore which can be called upon to cause trouble for other people.** Reflecting on this move from practical explanations to those founded on traditional beliefs, [18] notes that anything out of the ordinary is considered by the Shona (originally from Zimbabwe) to have been caused by spirits angered by witchcraft or sorcery. Indeed, the birth of a child with albinism is often explained in such terms and the suggestion is that this is due to the influence of evil spirits. A local belief in the Venda region of South Africa is that the 'snake inside women' helps with the delivery of babies. The snake is considered to monitor and protect her pregnancy and it is only when the snake turns away that the pregnancy is left unprotected.

[9] states that the use of derogatory names for persons with albinism has led to communities condemning them based on the condition and disregarding their humanity. In East Africa, most of the descriptive terms used to refer to persons with the condition are derogatory and demeaning. They suggest a lesser being. In Kiswahili, a language spoken by millions in the region, the name for persons with albinism is Zeru Zeru meaning 'ghost-like creature' while others refer to them as 'mzungu' (meaning white person). While in some parts of the world the term 'albino' is accepted, it is

increasingly seen as derogatory because it puts the condition ahead of the person. Old ways of describing people who are different have **always** been derogatory, therefore it is better to use 'person with albinism' than 'albino' [14].

One common misconception about albinism is that it is contagious. Like people with leprosy or physical disabilities, people with albinism were traditionally segregated in much of Southern Africa. Today this continues as children with albinism are prevented from mixing with other children for fear of **spreading their** 'disease' [17]. Some people refuse to shake hands with people with albinism, which is particularly problematic in certain circumstances, such as, at funerals where it is customary to shake hands as a sign of condolence. Others refuse to sit next to people with albinism on a bus or train and do not like to share taxis with them. A Zimbabwean with albinism sums up this attitude, 'Some people will not touch what I touch; in the bus no-one wants to sit near me, refuse to shake hands with, share utensils, touch or come near me' [19]. Some people with albinism even find their own family members avoiding direct contact with them [20].

[21] states that, in some parts of Africa, people with albinism are perceived as 'sacrificial lambs', from the biblical metaphor for someone or something that is sacrificed for the good of others. These individuals are wanted for their hands or genitals which are considered to be the body's strongest parts. People with albinism are hunted for this purpose as they are believed by some to possess supernatural or magical powers and if someone is married to an albino it is believed that they will be a very lucky man or woman [21].

3. METHODOLOGY

This study **combined both exploratory and descriptive designs**. These designs allowed the study to be conducted in a natural and unchanged environment. In this regard, the researchers captured the role of social workers towards people with albinism through observation of communication during interviews. Therefore, the researchers had the opportunity to explore the services for people with albinism and describe them in more detail, filling in the missing parts and **expanding their understanding in this field**.

The study used the snowball sampling technique. This enabled the respondents to refer the researchers to other people in their social network, who contributed towards the study. **For this study, the sample size consisted of fifteen (15) respondents aged 21 to 50 years, and the key informants who were; one (1) social worker, one (1) employee from the Office of the President (Disability Unit), and one (1) philanthropist were selected through snowballing process. The researchers requested the Chairperson of the Tshimologo Association of People with Albinism to help with identifying respondents and suggest other people who might be included in the study. This was done until the targeted sample size of fifteen (15) was reached.** A sample size of not more than 30 participants is ideal for qualitative

Formatted: Indent: First line: 0"

research because in-depth interviews are time consuming [22]. The study was cross-sectional, carried out at one point in time or over a short period.

Researchers incorporated document analysis to give voice and meaning by interpreting documents on the assessment topic. Documentary analysis involved reading secondary material, however, less research has been conducted in Botswana regarding albinism. There is limited secondary materials from agencies and government departments to guide the interpretation of experiences encountered by people with albinism. Meanwhile, the researchers relied on documentary data from different countries globally and regionally.

During the interviews, researchers utilized a code sheet for data reduction. This method allowed the researchers to arrange data in thematic forms that are manageable. It also allowed the researchers to have a column where findings were captured.

4. RESULTS

Respondents were asked to indicate their life experiences; Issues surrounding stigma and discrimination; myths associated with albinism; labelling; fear of contagion; teasing; being stared at; and unemployment.

The findings revealed that many people with albinism experience stigma and discrimination in their different locations. These include the communities in which they live, schools, workplaces, hospitals, clinics, government offices, neighbourhoods, and towns. They reported that people stigmatise them and do not want to associate with them because of their condition. One respondent described the experience as:

“When I grew up, my family was ashamed of me and hid me from the community. My parents took me to the cattle post and did not want me to go to school. In my community, they discriminated against me, and I was not accepted hence giving my parents a good reason to keep me away from the community. People did not want to touch me, called me names, such as (lelobo), and they would say this phrase repeatedly when they saw me (lelobo lelobo fetola mmala)” (chameleon, chameleon change your colours).

Another respondent stated that life is complicated by the way people treat and discriminate against those with albinism. This is because some cultures believe in horrible myths about PWA. Myths that PWA are not human and never die, that albinism is a curse from the gods, and that anyone who touches them will be cursed. The respondent further said that:

“When I grew up, people did not want to play with me and looked at me as if I was some kind of rubbish”.

Formatted: Indent: First line: 0"

Formatted: Indent: First line: 0"

Another lamented:

*“I grew up in very harsh and difficult **circumstances**. It was not easy, especially at school. Children did not want to sit next to me, and teachers did not take into consideration my sight problems as well as my slow pace. A few teachers tried to enlarge the font when writing notes on the board or printed notes for me while some did not care and used a small font which was difficult for me to see. People did not want to associate with me in any way and discriminated against me. They did not recognize me as a human being. My family and extended family have accepted me, I only experienced challenges with other community members who called me albino and looked down upon me. Neighbours during ceremonies such as weddings or funerals would not want me to touch food or peel any vegetables. It is common that, on such occasions, we offer help but, in my encounters, they did not want me to do activities such as cooking or slicing vegetables. Instead, they would say I should wash the dishes or pick up litter”.*

Many of the respondents (15/16) indicated that it is very difficult to build a bond with people generally, particularly teachers and other children at school. There is less support and encouragement, especially from teachers.

Formatted: Indent: First line: 0"

In reaction to stigma and discrimination, respondents stated that they face harsh conditions as they grow up and are raised in a very difficult and discriminatory environment. They are denied leisure activities, such as, playing sport. Some of those with Albinism are kept away from cities and hidden at the cattle posts/fields to protect them from the direct discrimination against them. Some parents/families do not accept them which leads to their marginalisation and being hidden away from the community.

4.1 Discrimination by and Against Families Including Members with Albinism

Findings showed that some people with albinism are discriminated against by family and community members and abused because of their condition. Most respondents (14/16) reported that some people, especially those expecting or having given birth to children with albinism, kill them due to the pressure from other families and community members. Some communities tend to believe that a family with a child with albinism is covered with a dark cloud, bewitched, and attacked by evil spirits. One male responded:

Formatted: Indent: First line: 0"

“Yes, our families are still discriminated against because of perceptions that people are holding about albinism and families will not want to be associated with a family that has a member with albinism. Some say they do not want to be affected by the sins of that family”.

4.2 Discrimination in Urban and Rural Areas

Accordingly, discrimination in cities and villages (11/16) respondents reported that growing up in rural areas as a person with albinism is not easy. It is much easier in towns as it possible to move from one point to another without being exposed or burnt by the sun because people use cars or combis.

Formatted: Indent: First line: 0"

One respondent said:

“Life in cities accommodates everyone because people mind their own business unlike in villages (rural areas) where there is much gossip among village members. The other time I went to some fields with my friend. From the bus stop, we walked a very long distance to reach our destination in the sun. I can imagine what people with albinism in rural areas go through and they experience negative treatment more often. I remember the very first time I went to town. It is when I applied for tertiary school. I did not know Gaborone very well at that time. I only knew Maruapula, where I stayed with a relative. Because I did not know how to move about in Gaborone, I had to ask for directions from people. The first person I asked for directions to Game City mall “gave me a negative attitude” as well as the second person. They just looked at me as if I was some kind of rubbish. The third person was so impatient and felt I was wasting her time as she was in a rush. The fourth person gave me directions but distanced himself from me. Those who gave me a negative attitude, they continued to walk as if I was not talking to them. It was obvious that they did not want to talk to me. Again, people in cities/towns seem to have little knowledge about albinism as compared to people in rural areas who are somehow stuck and still uphold negative cultural beliefs and certain myths about people with albinism. I remember the other time I was in Palapye volunteering and was part of an activity organized by Peace Corps USA. In this activity, the main aim was to bring together vulnerable children and teach them life skills. Some of the children who attended the training were from areas surrounding Molepolole and when they saw me, they touched their belly bottom. From what I heard they did so because they have been told that if you see someone with my albinism condition, they should touch their belly bottoms so that they do not give birth to a person with albinism when they grow up”.

Overall, respondents stated that in towns/cities the lifestyle is fast, and people socialise and interact with only those close to them. With busy schedules and lifestyles, people tend to focus on their own issues unlike in rural areas where people are interested in other people’s lives and gossip about them.

Formatted: Indent: First line: 0"

The other respondents (5/16) stated that life is better in the rural community because of a smaller population which makes it easier to socialize and interact at that level. In cities, however, people

stare too much and consider people with albinism to belong to a different place. Even in shops there is too much staring which makes them uncomfortable.

4.3 Myths and Superstitions Regarding Albinism

According to myths and superstition about albinism, it was established that there are certain ideas that people still hold and that affect the respondents' everyday life. Most respondents expressed their concern about the most common myth that people with albinism do not die naturally but simply disappear or vanish. One female stated:

“There are myths that we make powerful, strong concoctions and that we have so much luck. Through such myths, people with albinism are killed and this is hidden because there is a myth that says ga re swe ra nyelela (we do not die but disappear). In the past children were killed immediately as it was believed to be a curse and, when asked, families will just say motho yoo o nyeletse (the person has disappeared)”.

Many respondents indicated that the bad experiences of people with albinism are influenced by myths and superstition, such as, they have powers to make one rich, they do not die, but they vanish. These are based on the beliefs that people with albinism are offspring of parents (or a mother) who are punished by God for their sins.

There is consensus amongst respondents that people still believe myths about albinism. One of these is that, if someone touches a person with albinism, he/she will contract the condition. Another myth is that when one talks to a person with albinism, he or she will give birth to a child with albinism. In addition, one respondent reported that it is believed that, if a person has sexual relations with a person with albinism, he or she will give birth to a child with albinism and when one shares food from the same dish with a person with albinism one will give birth to a child with the condition.

With respect to myths and superstitions towards people with albinism, respondents indicated that they fear for their lives as people might do anything to ascertain whether such beliefs are true.

One respondent stated that:

“Myths towards us are so intense; people believe that every part of our bodies has powers, from our hair, nails, and to other parts of the body (pheko tsa rona di bogale thata). However, I wonder if we have so much power as people with albinism, why would not we use those powers to our advantage and make ourselves rich? The luck that people want from us, our body parts-why is it that we do not use it for our benefit? We live in fear (re tshela jaaka bo mmutla), we live in fear, wondering what would happen to us because of what people think.” “I walk every day from work to home, and when people offer me a ride, I ask myself

Formatted: Indent: First line: 0"

Formatted: Indent: First line: 0"

questions whether it is a genuine ride or my life, is in danger because of the beliefs they might have about us.

In reaction to myths and superstition about albinism, respondents stated that they have seen people spit saliva and touch their belly bottoms, because it is believed that they will not give birth to a child with albinism. In addition, some people go down on their knees when they see people with albinism. However, all this is learned from the cultural beliefs.

Formatted: Indent: First line: 0"

4.4 Labelling and Use of Derogatory Names

Accordingly labelling and name calling, many respondents (14/16) mentioned that people disregard their humanity. Commenting on labelling and name-calling, one respondent said that:

Formatted: Indent: First line: 0"

“People call us names such as albino, lekgoa, lechaene, and sepoko and it is not appropriate; the names somehow are derogatory against us and make us feel like we are not human beings. It is better to say, ‘person with albinism.’ The names and labels do not take into consideration that we are human beings as well. It is like they refer to an object or something else and put our condition before humanity (ba eteletsa boswafi ko pee, motho ko morago).”

Among the 14 respondents who did not tolerate the labelling and name calling, one reported:

“I grew up being called an albino and we were regarded as objects; we were undermined, and people perceived us as useless people who could do anything. They believed we were punished by God. They did not see any potential in us, that is why they called us albinos and that to me showed a lack of knowledge. Even the children, when they grew up, could differentiate between us and other people without albinism yet they looked at us as if we were objects. In some cases, we were called white people and they would say we are not white people we are things called albinos. We grew up with that stigma, and few understand our condition and that we are human beings. With time I managed to accept myself and started to relate and show people who called me albino that it was not appropriate.”

A feature that troubled the respondents is that young children learnt to label people with albinism because of the socialization and the community perception of albinism.

Formatted: Indent: First line: 0"

Meanwhile, 2/16 respondents differed from others because they stated that they did not have any problem with name-calling because they have learnt to accept it. One said:

“People call us names such as albino. The name is very weak and discriminatory. It is better to say a person with albinism just as one can say a person with a disability and not a disabled person. Not all people with albinism have accepted themselves and some are offended when referred to as an albino, but I personally do not care much. In some instances, people will call one an albino not meaning to discriminate. With the self-esteem I have, I do not mind the

word albino but when I grew up, I had no confidence, and the word albino hurt me so much. The word albino does not show respect and it is not even polite. It takes courage for one to accept him/herself first and then the word will not hurt much.”

Another respondent remarked that:

“I have no problem with being called an albino, I have learnt to accept the word. It also depends on how one uses the word. Some use it to praise while others use it to belittle and look down on us, but I have learnt to live with it.”

4.5 Fear of Contagion, Teasing, and Staring

Half of the respondents (9/16) expressed that one common misconception about albinism is that it is contagious. They stated that wherever they go people make negative comments and some are afraid to stare at them. They further elaborated that some people refuse to shake hands with them which is particularly problematic at a funeral where it is customary to shake hands as a sign of condolence. Others refuse to sit next to people with albinism on a bus and do not like to share taxis with them. One respondent summed up this attitude thus:

“Some people will not touch what I touch, even at weddings or funerals, and in the combis and taxis, noone wants to sit next to me. It is that they cannot say it but mostly their nonverbal communication says it all.”

Briefly, respondents reported that people refuse to shake their hands, share utensils, touch, or come near them, and some people with albinism even find their own family members avoiding direct contact with them.

In summary, one respondent said:

“Some people say they get uncomfortable (ba sisimoga) when they see us. Even today some people cannot use the same cup or plate that has been used by a person with albinism or share a meal with us. At funerals and weddings, some people will not want us to assist in any way. At work, my supervisor once said I should not touch vegetables and fruits and some customers may not want to buy the products.

4.6 Unemployment

Many respondents reported they are unemployed, deficient in performance at school, and do not possess a Secondary school Certificate taking into consideration the limited employment opportunities in Botswana. They further reported that discrimination and negative attitudes limits their chances of

Formatted: Indent: First line: 0"

Formatted: Indent: First line: 0"

Formatted: Indent: First line: 0"

employment because no one wants to hire a person with albinism despite the necessary skills. One female respondent said:

“The other time I was looking for a job and one of my relatives had a friend who was looking for a helper at home, so she recommended me to work for the lady. My relative did not tell her friend that she had recommended someone with albinism and when I finally met with the lady who wanted a helper, she was shocked and told me that I cannot work for her because her children will be afraid of me. Also, she has never related with someone of my condition, and I ended up not getting the job because of the condition.”

5. DISCUSSION

The findings reveal that many people with albinism experience stigma and discrimination in different settings. These include the communities in which they live, schools, the workplace, hospitals and clinics, government offices, and various locations such as neighbourhoods and towns. This is supported by [9] who stated that persons with albinism continue to suffer stigma, prejudice, stereotyping, and discrimination. It is a condition that cannot be hidden and, when a person with albinism is in a group of dark-skinned people, he/she stands out as different. They are a visible minority and, in many parts of Africa, are subject to open discrimination. They are shunned by their families and accused of being cursed, unclean, and witches. In addition, children with albinism are hidden from the public, forbidden from socializing with others, and treated as outcasts which is evident with some respondents.

The findings and literature are constant with Maslow's hierarchy of needs. [23] devised the hierarchical structure in which, he postulated that lower-level needs must be fulfilled before a person can reach the high level of self-actualization. He further stated that a self-actualized person is someone who has satisfied all the lower-level needs of safety, belonging, love, and respect. Like others, individuals with albinism need to go through these levels to be satisfied in life.

According to [24], all human beings want to 'belong', and every individual is born within a social context, if individuals are without other human beings around them for nurturance, they die. From Maslow's perspective, belongingness, means that an individual who is part of a group is accepted and valued by the members of that group. However, to belong requires a mutual sense of oneness. For self-esteem to be operative, it is not only necessary that the group accepts the individuals but that individuals regard themselves as belonging. They must see themselves as accepted and valued members of the group. According to [23], the need for safety, belongingness, love relations, and respect can be satisfied by other people.

With that said people with albinism fail to reach the last stages of the hierarchy. This is due to the negative attitudes, discrimination, and stigma that are portrayed by different communities. Having

Formatted: Indent: First line: 0"

physiological needs met does not necessarily mean that one is happy. People with albinism might have their physiological needs met but, as they progress to other stages that include the need for belonging and love, and affection, relationships such as friendships, romantic attachments, and families help fulfill these needs for companionship and acceptance, as well as involvement in social, community or religious groups. Because of different attitudes, these needs might not be met resulting in people with albinism not being able to reach self-actualisation. Without love and a sense of belonging in the community, interaction and establishing relationships become a challenge for them. This makes it difficult to develop high self-esteem, personal worth, social recognition, and accomplishment which leads low self-recognition, failure, or inferiority.

5.1 Discrimination by and Towards Families Including Members with Albinism

Findings showed that some people with albinism are oppressed and discriminated against by their family and community members and some are abused because of the condition. Many respondents (14/16) reported that some people, especially those with children with albinism, kill them due to pressure and discrimination from families and community members. Some communities tend to believe that a family with a child with albinism is covered with a dark cloud or has been bewitched.

This corresponds to the findings by [17] that families of people with albinism are discriminated against because it is believed that the woman had sex with a tokoloshe (zombie). They claim that the mother had sex with a white man or that the parents have done something bad and are being punished by the Almighty. Therefore, people decide to distance themselves from those concerned. To support this, the social learning theory states that people can learn by watching other people perform the behaviour [25]. This suggests that some people may learn and adapt to this attitude and behaviour of discriminating against families and people with albinism.

5.2 Discrimination in Urban and Rural Areas

The findings show that treatment in urban areas is better than in rural areas. In towns/cities, the lifestyle is fast, and people socialize and interact with only those close to them. With busy schedules and lifestyles, people tend to focus on their own issues yet in rural areas people are interested in other people's lives and gossip about them. In cities, however, people stare and consider people with albinism as belonging in a different place. Even in shops, there is a great deal of staring which makes them uncomfortable. [25] stated that, by observing the behaviours of others, people develop similar behaviours. After observing others' behaviour, people assimilate and imitate those behaviours, especially if their observational experiences are positive or include rewards related to the observed behaviour [25]. Therefore, the social learning theory states that people learn by observing, rehearsing and retention [25]. In this case, when other people stare or behave in a certain manner towards people with albinism, other people who have observed that behaviour will also portray the same behaviour when they encounter people with albinism.

Formatted: Indent: First line: 0"

5.3 Myths and Superstitions Regarding Albinism

The results show that there are myths and superstitions people hold that affect the respondents' everyday social life. Many expressed their concern about the myths that state people with albinism do not die naturally but simply vanish and have powers for luck. A few studies, such as that by [5] found that myths and superstitions about albinism affected the participants' life and self-image. The most common myth is that people with albinism "do not die naturally but simply disappear or vanish." Nevertheless, [11] argues that the problems experienced by persons with albinism do not necessarily relate to their obvious physical difference in terms of skin colour but to the social environment which is also influenced by myths and superstition. On the other hand, [10] found the myth to be most common amongst the South African black population and the product of a woman with a water spirit.

5.4 Labelling and Use of Derogatory Names

The study has shown that people with albinism are labelled and called names. A majority of respondents (14/16) mentioned that they are called names and labelled in a way that disregards their humanity. Commenting on the issue of labelling and name calling, they stated that people call them names such as albino, lekgoa, lechaene, sepoko which is not appropriate. The names make them feel that they are not human beings. The names and labelling do not take into consideration that they are human beings. They feel like objects and that their condition is given priority over their humanity.

[9] confirmed that the use of derogatory names for persons with albinism has led communities to condemn them based on their condition and disregard their humanity. In East Africa, the descriptive terms used to refer to persons with the condition are derogatory and demeaning. They seem to suggest a lesser being. In Kiswahili, a language spoken by millions in the region, the name for persons with albinism is Zerumeaning 'ghost-like creature' while others refer to them as 'mzungu' (meaning white man). While in some parts of the world the term 'albino' is accepted, it is increasingly seen as derogatory because it puts the condition ahead of the person. Traditional ways of describing people who are different have always been derogatory, therefore it is better to use 'person with albinism' rather than 'albino' [14].

However, the findings and literature support the social learning theory. The principles of social learning are assumed to operate in the same way throughout life and observational learning may take place at any age. Social learning theory posits that people learn from one another, through observation, imitation, and modelling. Based on these general principles, learning can take place without a change in behaviour. The social learning theory states that people can learn by watching other people perform the behaviour. Observational learning explains the nature of children

learning behaviours by watching the behaviour of the people around them and eventually imitating them.

Therefore, this suggests that children learn and adopt the attitudes, beliefs, and behaviour (such as and name calling towards people with albinism) from the people around them being parents, family, and the community. The findings from the study showed that at times, when children come across people with albinism, they would say, “mother, there is a white person,” and the mother or parent mostly will respond by saying “It’s not a white person but an albino.” This explains that they observe how the people around them interact with, react toward people with albinism, and imitate the behaviours observed.

5.5 Fear of Contagion, Teasing and Staring

A study by Lund [19] raised issues of fear of contagion. In the present study half of the respondents (8/16) stated that one of the most common misconceptions about albinism is that it is contagious. They said that wherever they go people make negative comments about them. They further elaborated that some people refuse to shake hands with them which can be particularly problematic in certain circumstances where it is customary to shake hands. Others refuse to sit next to people with albinism on a bus and do not like to share taxis with them. This was reinforced in a study [26] where respondents stated: ‘When we get into taxis, people still move to the other side or even refuse to use that taxi. We are still called isishawa (a Zulu word for a person who is cursed) and inkawu (an Nguni word for ‘white baboon’). Findings of the current study also revealed that some refuse to shake hands with people with albinism, which can be particularly problematic in at a funeral where it is customary to shake hands as a sign of condolence. Some people with albinism even find their own family members avoiding direct contact with them [20]

Formatted: Indent: First line: 0"

5.6 Unemployment

The results show that most respondents are faced with the challenge of unemployment. Because of not doing well at school and most of them having Secondary Certificate is a serious challenge taking into consideration that there are no employment opportunities in Botswana. They further mentioned that being discriminated against and faced with negative attitudes limits their chances of employment because no one want to hire a person with albinism even when they have the skills.

Formatted: Indent: First line: 0"

Maslows’s hierarchy of needs explains that the lowest levels of the pyramid are made up of the most basic needs, while the more complex needs are located at the top of the pyramid. Needs at the bottom of the pyramid are basic physical requirements including the need for food, water, sleep, and warmth. Once these lower-level needs have been met, people can move on to the next level of needs which are for safety and security [23]. As people progress up the pyramid, needs become increasingly psychological and social. Soon, the needs for love, friendship, and intimacy become important.

Further up the pyramid, the need for personal esteem and feelings of accomplishment take priority. Maslow emphasised the importance of self-actualisation, which is a process of growing and developing as a person to achieve individual potential.

However, it is difficult for people with albinism to reach their self-actualisation level. This is so because, in most cases they are not working because of lower qualification such as junior certificate and Cambridge certificate. Reason being the uncondusive learning and not taking into consideration their sight problems. Having said that, they fail to find job opportunities because of lower qualifications, stigma, and discrimination against them. Because of not having employment opportunities, their basic needs are not met, thus making it difficult for them to move to the next levels such as feeling accepted, safe, and being secure. Not being able to move to the next level, destroys their esteem and confidence thus resulting in them not being able to establish friendships and intimacy which then leads to them not being able to integrate and socialise with other people. All this prevents the individual from reaching their self-actualisation. If their basic needs are met from the beginning it enables them to move on to the other levels, resulting in self-actualisation.

6. LIMITATIONS

The current study is exploratory thus it provides insights into experiences encountered by people with albinism. Secondly, Botswana is a large country as well as the city of Gaborone, thus the study sample was drawn from Gaborone and cannot be representative of all people with albinism in Botswana. Additionally, the sample size limits the generalizability of findings to the entire Gaborone.

Formatted: Indent: First line: 0"

7. IMPLICATIONS

The study has important implications for People with Albinism in Botswana and social assistance and protection in general. The present study indicated that people with albinism continue to be marginalized and not much has been done by social workers to assist and enhance the wellbeing of people with albinism. The study may help practitioners, such as social workers, counsellors, health workers, and teachers, and through them and through other means, community members, to understand the nature of albinism and the effects of negative behaviour/attitude towards those affected. The findings and recommendations are vital with regard to advocacy concerning design of interventions and implementation of programmes to address, reduce and prevent such stigmatization and discrimination. Human rights organizations may learn from the research the depth of suffering endured by those living with albinism (and their families) and translate the reviews/findings into self-help initiatives at community level.

Formatted: Indent: First line: 0"

Challenges and issues surrounding people with albinism are social issues, globally, regionally, and locally, not only for individuals, groups, families and societies but also for policy makers. Therefore, this study may give rise to the enactment of policies in the fields of health, education and human

rights in general. Including people with albinism in health policies will take into consideration the fact that they have special needs regarding physical health. In addition, the study may also consider inclusion of young people with albinism in the education policy, with a focus on the challenges they face in the education arena.

FINDINGS from this research may contribute to existing body of knowledge in many professional arenas, particularly education, with reference to experiences encountered by people with albinism during interaction with other community members. The study may point to the need for research that may be wider in scope and covering more geographical areas and different types of issues surrounding albinism. The study is significant in the sense that little research has been conducted in this field in Botswana. The research may also raise more questions and expose gaps that will require further investigation involving multi-disciplinary approaches and methodologies.

8. CONCLUSION

The study explored the life experiences of people with albinism in Gaborone. The study show that albinism is still, both socially and medically profoundly misunderstood. The physical appearance of persons with albinism is often the object of erroneous beliefs and myths (influenced by superstition) which foster their marginalisation and social exclusion. The findings revealed that people with albinism experience challenges such as stigma, discrimination, and prejudice. This extends to their families in urban and rural areas. Furthermore, myths and superstition are associated with albinism, as are labelling and use of derogatory names, negative attitudes, fear of contagion, teasing and staring, and unemployment. In conclusion, the study allowed the voices of a group of persons with albinism to be heard and the message that came across strongly was the need to enhance knowledge and awareness of the condition. Above all, a humane and caring society would be created in which the rights of all groups are respected, including those with albinism.

9. ETHICAL CONSIDERATION

The consideration of ethics in research is of paramount importance. It is therefore critical that the researcher takes this into account while conducting research to avoid causing unintended harm. [27] contend that the researchers must identify ethical issues concerned with doing no harm to the participants and taking responsibility for the consequences of their involvement. The discussion below includes the ethical principles that guided the researchers as they engaged in the study:

Informed consent: The researchers requested permission from participants before conducting the interviews. They further informed them that they intended to use a tape recorder during the interviews to capture each respondent's every word. This was done though signing a consent form.

Withdrawal from the process: The researchers notified the respondent chosen that if, at any point, they felt uncomfortable with the study, they could withdraw.

Anonymity: The researchers also informed the participants that they would remain anonymous. Their names were not included in the analyses to ensure that their identities were not revealed.

Confidentiality: During the study, the researchers assured the participants that the source of the information was not be shared with the public. All information and records were kept confidential. In addition, researchers did not take any photographs of the participants.

Dissemination of Results: In publication of the results of the study, the researcher ensured that she preserved the accuracy of the results obtained. These were made available to the Ministry of Local Government and Rural Development, Tshimologo Association for People with Albinism, and the ministries of Health and Education as well as other organisations that wished to make professional and ethical use of the study.

Ethical Clearance: Thereseachers handed her proposal to the Institutional Review Board who granted her permission to conduct the research.

REFERENCES

1. McBride, G. R. (2014). Oculocutaneous albinism: An African perspective. *Br Ir Orthopt J* 2014; 11, 3–8.
2. Winship, W.S.(2003). Handbook of genetic and congenital syndromes, 1st edition. Oxford University Press, Cape Town.
3. Christianson , A.L., Howson, P. & Modell, B. (2006). Global Report on Birth Defects: *The hidden toll of dying and disabled children*, White Plains, New York.
4. Save the Children Research Report. (2001). <https://www.savethechildren.net/search/node/stigma>.
5. Poee-Monyemore, Mmuso B.J., Mavundla, Thandisizwe R., & Christianson, Arnold L.(2012). The experience of people with oculocutaneous albinism. *Health SA Gesondheid (Online)*, 17(1), 1-8.

Comment [NA1]: All works cited in the text must be listed in the References.
to elaborate the bibliographic citation and references format according to the needs of CIAST.

Formatted: Indent: First line: 0"

6. Kromberg J.G, Castle D, Zwane E.M, Jenkins T. (1989). Albinism and skin cancer in Southern Africa. *Clin Genet.* 1989 Jul;36(1):43-52. Doi: 10.1111/j.1399-0004.1989.tb03365.x. PMID: 2766562.
7. Kromberg, J. G., & T.Jenkins. (1982). Prevalence of albinism in South African Negro. *South Africa Medical Journal*, No 61, 383-386.
8. Main, M. (1987) *Kalahari: Life's Variety in Dune and Delta*. Southern Book Publishers, Johannesburg.
9. Thuku (2011). Myths, Discrimination, and the Call for Special Rights for Persons with Albinism in Sub-Saharan Africa. http://www.underthesamesun.com/sites/default/files/MYTHS.Final_.pdf.
10. Kromberg, J.G., Zwane, E.M., Jenkins, T., 1992. Albinism in the South African negro. IV. *Attitudes and the death myth. Birth Defects* 28, 159–166.
11. Gaigher, R.J., Lund, P.M., Makuya, E. (2002). A sociological study of children with albinism at a special school in the Limpopo province. *Curatationis*, 4-11.
12. Poee-Monyemore, M.B.J. (2003). 'Integration of children with disabilities into the community: The role of the community nurse', Master's dissertation, MA (Cur), Department of Health Studies, University of South Africa, Pretoria.
13. Link, B. G., & Phelan, J. C. (2001). Conceptualizing Stigma. *Annual Review of Sociology*, 27, 363–385. <http://www.jstor.org/stable/2678626>.
14. Small, V.A. (1998). *Sociological studies of people of colour with albinism. Zebracorn*, <http://www.zebracorn.com>.
15. Daniel, I. A. (2015). Socio-cultural conception of albinism and sexuality challenges among persons with albinism (PWA) in South West-Nigeria. *International Journal of Arts and Humanities vol 4 (2)*, 189-208.
16. Jordaan, W. & Jordaan, J. (1998). *People in context. 3rd edn.*, Heinemann, Johannesburg.
17. Baker, C., Lund, P., Nyathi, R., & Taylor, J. (2010). The myths surrounding people with albinism in South Africa and Zimbabwe. *Journal of African Cultural Studies*, 22(2), 169-181. <https://doi.org/10.1080/13696815.2010.491412>
18. Bourdillon M. F. C. & Phil D. (1982). *The shona peoples : an ethnography of the contemporary shona with special reference to their religion* (Revised). Mambo Press.
19. Lund, P.M. (2001) Health and education of children with albinism in Zimbabwe, *Health Education Research, Volume 16, Issue 1, February 2001, Pages 1–7*, <https://doi.org/10.1093/her/16.1.1>
20. Onoja, R., and A. Airahoubor. (2006). Albinos: tales of mockery, rejection. *Newswatch*, December 18, 49–55.
21. Ntinda, R. N. (2008). Customary practices and children with albinism in Namibia: A constitutional challenge? Children's rights in Namibia. <http://en.afrik.com/article13487.html>. Viewed 20 October 2020.
22. Bailey, K. (2008). *Methods of Social Research, 4th Edition*. New York: Simon and Schuster.

23. Maslow, A. H. (2012). *A theory of human motivation*. United States of America: Start Publishing.
24. Felker, D. W. (1974). *Building positive self-concepts*. Minneapolis: Burgess.
25. Bandura, A. (1977). *Social Learning Theory*. Englewood Cliffs, NJ: Prentice Hall.
26. Fazel, A. (2012). “Albinos” lonely call for recognition’, *Mail & Guardian Health Supplement*, 18–24.
27. Engel, R. J., & Schuitt, R. (2009). *The practice of research in social work* . California: Sage.
28. Andersson, L. J. (2015). *Albinism: when skin becomes a death sentence*. Sweden: Linnaeus University, Växjö.
29. Palmer, C. (2007). Myths, stereotypes and self perception: The impact of albinism on self esteem *British Journal of Visual Impairments*, vol 25 (2), 917-921.
30. Under the Same Sun [UTSS]. (2012). *Children with Albinism in Africa: Murder Mutilation and Violence: A Report on Tanzania*. Vancouver, Canada: Under the Same Sun.
31. Under the same sun. (2015). *Reported attacks of persons with albinism: Most recent attacks included*. Tanzania.
32. Burke, J. (2012). Discrimination and violence against Tanzanians with albinism in the Great Lakes region: Crime and national shame. Australia: *35th AFSAAP Annual Conference Proceedings*.
33. Tambala-Kaliati T, Adomako EB, Frimpong-Manso K (2021). Living with albinism in an African community: exploring the challenges of persons with albinism in Lilongwe District, Malawi. *Heliyon*. 12;7(5):e07034. doi: 10.1016/j.heliyon.2021.e07034. PMID: 34136675; PMCID: PMC8180609.
34. Taylor, C. B. (2010). The myths surrounding people with albinism in South Africa and Zimbabwe. *Journal of African Cultural Studies* vol 22 (2), 169-181.

Comment [NA2]: These should be checked (in the text).