

# Challenges Pupils with Albinism face in Selected Schools of Luapula Province, Zambia

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**Abstract:** The aim of this study was to investigate the challenges pupils with albinism face in schools. It was a case study which comprised of thirty (30) participants from St. Mary's Girls Secondary School and St. Mary's Special School for the Visually Impaired in Kawambwa. This study was qualitative in nature. Interviews and focus group discussions were used to collect data. A descriptive research design was used. The key findings of the study revealed that pupils with albinism were not accepted but discriminated by their fellow pupils who were not albinos and some teachers. The pupils also faced problems with teaching and learning materials which were not user friendly. Further, the findings revealed that pupils with albinism had low self-esteem compared to those without albinism as a result of the challenges they faced. Based on the findings, this study recommends there should be psychological intervention programmes which include assertiveness training and personal coping skills for pupils with albinism in schools so as to continue to strengthen their self-esteem and assertiveness. The study further recommends that when designing education policies, policy makers should not only consider the academic, but also the physiological and the psychological needs of learners with albinism with the aim of protecting their rights.

**Key Words:** Albinism; Self-Esteem; Visually Impaired; Stigma; Discrimination

## I. BACKGROUND AND CONTEXT

### i) Understanding Albinism

Zambia, like other countries, has adopted an inclusive education system through a national policy document 'Educating Our Future' of 1996 (MoE, 1996). This document is seen as the first commitment to inclusive education which is aimed at helping learners foster the necessary knowledge, skills and values in achieving 'Education for All.' According to Arduin (2015), inclusive education is based on human rights and social practice. In a report by the United Nations High Commission for Human Rights (UNHCHR) (2013), albinism could be considered as a disability under the convention on the Rights of Persons with Disabilities. According to article 1 one of the convention, persons with disability include those who have long-term physical, mental, intellectual or sensory impairment which in interaction with various barriers may hinder the full and effective participation in society on an equal basis with others. Furthermore, article 19 of the UN Convention on the Rights of People with Disabilities (2006) underpinned the importance of life in and as part of the community for people with disabilities. This

means that albinos should enjoy equal rights with those that are not albinos.

Albinism is a genetic deficiency of melanin pigment production. According to Central Statistical Office (CSO) (2012) albinism is defined as people with a condition where they have little or no pigment in their eyes, skin, or hair. This means that it is a condition inherited. National Organisation for Albinism and Hypo pigmentation (NOAH) (2010), defines albinism as an inherited generic condition that reduces the amount of melanin pigment in the skin, hair and /or eyes.

Albinism is generally classified into two types, namely; Ocular Albinism and Oculocutaneous Albinism (Selepe, 2007). When only the eyes are affected, the condition is called Ocular Albinism, whereas when both the eyes and the skin are affected, the condition is called Oculocutaneous Albinism (Oetting, Brillian and King, 1996; Nebre, 2018). Oculocutaneous Albinism is a recessive genetic condition prevalent throughout sub-Saharan Africa. In indigenous Black populations, Oculocutaneous Albinism subjects have sandy coloured hair, pale chalky white skin, often burned by the sun and blue to light brown eyes showing nystagmus (rapid eye movements), photophobia, lack of binocular vision and poor acuity (Gaigher, Lund and Makuya, 2002). Albinism is caused by albinism genes called heterozygous from both parents. It is never caused or determined by one parent, if a woman is heterozygous and a man is heterozygous the possibility of producing an albino child is high. Unlike where the woman is homozygous and a man is heterozygous, the parents never produce an albino child. Also, if the woman is heterozygous and a man is homozygous, production of an albino child may not take place. The gene which cause albinism is recessive to the gene of normal skin colour. This is where a single gene with alleles controls the production of melanin. One allele (A), codes for melanin production, the other (a) does not. This is so because the gene which causes albinism is recessive. Therefore, if an individual who is heterozygous mates with another individual who is homozygous, the child will have normal skin pigmentation. It is only the case of an individual who is heterozygous who mates another heterozygous will have a child with albinism. Lack of light pigmentation results into having photoreceptors being damaged due to high light intensity. This means that schools are to enhance how to be responsible and learn how to deal with their low visual impairment disability.

*ii) Characteristics of Albinos*

Therefore, the following are the characteristics of albinos:

- White skin, white hair and pink eyes.
- Eyebrows and eyelashes are whitish.
- The rapid eye movements or jerking of the eyeball which is as a result of the condition known as nystagmus caused due to too much light. Nystagmus is involuntary movement of the eyes that can cause fatigue when carrying out visual tasks. Nystagmus is associated with many eye conditions or it may be the only diagnosis identified by an ophthalmologist.
- In a person with albinism rods are more active than cones hence they see well where there is less light. In the normal eye, the retina in the area called macula two cells are found, these are the rods and cones. Cones are responsible for fine clear vision while rods for peripheral vision or dim kind of vision.
- Persons with albinism have reduced or poor visual acuity are sensitive to light.
- Persons with albinism are sensitive to sunburn, skin lesions and cancers
- Persons with albinism have large refractive errors, and a lack of binocular vision
- They have social problems and communication because most of the time they get second hand information.
- Usually dependent on others
- They have mobility problems.
- May have very little experience with the environment due to social isolation.

From the above characteristics, one would argue that albinism causes serious challenging to pupils with the condition.

*iii) Some Myths about Albinos*

Albinism can be found in all human races. However, it becomes more startling when it occurs in a dark-skinned person. Misunderstanding of the causes of Oculocutaneous Albinism is sometimes a catalyst for extra family stress and, a recipe for discrimination. The entails that there are many myths surrounding albinism. Initially, most husbands in Africa thought that their wives cheated on them with White males (Baker, Lund, Nyathi and Taylor (2010). This obviously brought out marital disputes which directly impacted on the educational support of pupils with albinism.

In a recent survey conducted by Machipisa (2002), results shows that more than 63 percent of children with albinism contacted in Zimbabwe come from broken homes. In most cases, a father abandoned his family when a child with albinism was born. Those fathers who opted to stay in the family often had a tendency of treating the child harshly and ridiculed. The child would be treated not as a member of the family as he/she would be seen as having brought shame to the whole family (Machipisa, 2002). In some cases, if the mother is stuck with child-care and custody, she may abuse or

even abandon the child. Contrary to these families, some parents, after their initial shock, accept these children and treat them as special gifts from God. They find these golden children attractive and are proud of them (NOAH, 2005). However, it appears the myths surrounding albinos in Africa are still strong, and unfortunately, this has been transmitted to schools.

*iv) Studies on Challenges Pupils with Albinism face in Schools*

Different research studies done by scholars such as Selepe (2007); Lund (2001); have indicated that most peers of pupils with albinism exhibit bad attitudes and lack of knowledge about albinism and this created bad relationships between pupils with albinism and those without the condition. In a study conducted by Lund (2001) on the health and education of children with albinism in Zimbabwe, results showed that pupils with albinism faced social problems in schools in that they were subjected to name-calling, were ridiculed and beaten by fellow pupils. They were avoided by their peers, who often refused to sit, eat, or play with them. These attitudes appeared to be painful experiences for small children who needed physical expression of love and care and for teenagers who are looking for group interaction and acceptance (Kromberg, Zwane and Jenkins, 1987). This situation makes learners with albinism to loose self-esteem.

Teachers play an important role in the lives of pupils of which pupils with albinism are not an exception. In Zambia, there are few special schools that can provide individualized educational programmes for learners with albinism with few teachers who are trained to handle pupils with albinism. However, most teachers portray good attitudes towards pupils with albinism and they also have knowledge about pupils with albinism. In a study conducted by Lund and Lynch (2011) in Malawi on the education of children and young people with albinism showed that teachers were positive towards children with albinism despite the challenges of insufficient training and large class sizes. In the same study, interviews with teachers revealed good practice towards pupils with albinism because children with albinism were encouraged to sit at the front of the classroom and were allowed to move close to the chalk board when necessary; teachers provided large print sheets for children with albinism; and also wrote in bold, clear letters on the chalk board and allowed people with albinism to wear their hats. The schools also encourage and support positive attitude towards albinism, and this enhances the learner's self-image and self-worth (Gaigher, Lund and Makuya, 2002). Some teachers also permit these learners to change their sitting positions, depending on where the work is being conducted. In some instances these learners are allowed to use their own textbooks, rather than sharing with others (Lund, 1997).

However, on the other hand, it has been reported that unsympathetic teachers often ordered these poor-sighted learners to sit down if they happen to stand up in order to reach the chalk board (Musiwa, 1998). According to Gaigher,

Lund, and Makuya (2002), learners with Ocular Albinism are often isolated from activities that stimulate cognitive and perceptual motor development because they cannot take part in outdoor activities and tasks. Because of the poor eyesight or highly sensitive skin, these learners often seem to be threatened when surrounded by the “normally sighted”, who exuberantly and confidently master new skills and play games from which they are excluded. This type of exclusion can be a significant barrier to learning and general well-being of learners with albinism.

There are a lot of challenges which pupils with albinism face in schools and some of these include social stigma and discrimination, lack of medical attention and inadequate educational provisions. According to Msomi (2014), stigma and discrimination have a damaging impact on the dignity and self-respect of learners with albinism. Therefore, these challenges albinos face require teachers who have the knowledge and skills to identify, assess and support them within and outside classroom.

In many parts of the world, persons with albinism are largely seen as being incomplete. Small (1998) argues that there is indeed a negative stigma attached to albinism as well as other special populations. She argues that in general, albinism is equated with, and categorized as a blemish, mark, stain, even disfigurement. That is, it is a visual stigma that makes society look at it with suspicion and fear. Unlike any other stigma, albinism is the only condition of any type mistaken for mixed race. People with albinism are also perceived to be inscrutable, sinister, less capable or having a character flaw. A study conducted by Small on people with albinism in Nigeria concluded that people with albinism may suffer socially and psychologically due to family and society's negative attitudes. The use of derogatory names for persons with albinism has led to prejudice and stereotypes which lead communities to condemn them based on the condition rather than appreciate their humanity first. Studies in East Africa have revealed that most of the descriptive terms used to refer to persons with the condition are derogatory and demeaning. The demeaning and derogatory names and terms against persons with albinism leads to discrimination based on colour.

Because of lack of melanin pigment, persons with albinism are pre-disposed to health problems of the skin and vision. Skin cancer cases are higher in persons with albinism due to the effect of ultra violet rays from the sun which causes lesions. To lessen the effects of the sun, persons with albinism need to apply sunscreens, wear hats and use special sunglasses which are costly and in most rural areas, unavailable. Many governments have failed to ensure access and affordability of these vital items. The national health systems have failed to factor in the needs of persons with albinism adequately. Small (1998) argues that aside from the sociological problems faced by people with albinism in underdeveloped and developing countries, health care is poor because the condition may not be seen as a true health concern. In these areas of the world, governments and the health structure may sometimes provide

persons with albinism with glasses, but not sunscreen, special low vision aids, or sunglasses making it almost impossible for a person living with albinism to spend much time outdoors. The health and employment structure may not help with getting an indoor job.

For years, learning institutions in Africa have put learners with albinism under the same conditions as other learners without taking into account the visual impairment associated with the condition. In other instances, learners with albinism are taken to schools for the blind when they are not blind. Poor vision may cause learners with albinism to be slow learners either due to inability to see the black board clearly or inability to read books and other learning materials. The text books and exam papers are mostly printed in normal fonts which may be hard for learners with albinism to read quickly. Learners with albinism have also been required to finish exams at the same time as other pigmented learners whose sight is normal. These condition makes it difficult for them to do well high in academics as compared with pupils without the condition.

As noted earlier, children with albinism face a lot of problems at school which further affect their academic performance. Because of their condition, many families frequently neglect the education of children with albinism as they believe their education is a waste of resources. Those who attend school often suffer from teasing and bullying from classmates. In some cases, their inability to see the blackboard owing to significant vision impairment, forces them to drop out of school. As a result, many have low education levels and do not have all the necessary social or economic tools to live productive lives. In a recent study in central Malawi supported by the Commonwealth Secretariat, Sight Savers International, Coventry University and the University of Birmingham on the outcomes of Special Educational Needs (SEN) revealed worrying evidence that some children with albinism were not attending school due to bullying by peers, lack of understanding from teachers or insufficient parental support, (Lund and Lynch, 2011). Although they have the ability to do better in schools, the effects of their conditions have led to poor academic performances and low education levels for persons with albinism. This in turn denies them livelihood options hence the abject poverty that many live in. Lack of education and life skills also limits their active participation in local, national and international affairs. Whether this is the case in Kawambwa district, this study has to establish.

Albinism in Zambia seem to be growing. As at 2010, the albino population at national level was 25,324. The population in rural areas was higher than urban areas at 16,937 and 8,387, respectively. Lusaka Province had the highest population of albinos at 3,495 while North-Western Province had the lowest at 1,387 (CSO, 2012). Most people appear not to be enlightened with regard to albinism because it is a rare condition. On the other hand, people with this condition appear to see themselves as being trapped in a situation of not

fully understanding whether they are a fit or a misfit in the society.

There seem to be various perceived societal attitudes towards people with the condition which vary from person to person at different stages of life. Children and teenagers with Oculocutaneous Albinism in the Zambian communities appear to be facing challenges that result in a range of social, psychological, and educational problems (Gaigher, Lund and Makuya, 2002). According to Magnus (1992), the functioning of people with this condition often seem to be hindered by the behaviour of fellow citizens, because in most cases these individuals seem to be treated like outcasts and shunned or sometimes even murdered. Children with this condition appear to be severely affected because they seem not to understand the difference between themselves and other individuals who are different from them. Because of this, they appear to be feeling isolated not only in physical appearance but also in conduct of everyday life, thus affecting their self-esteem (Lund, 2001).

Lund (2001) further states that children and teenagers with albinism also seem to continue to experience problems caused by their conditions both at school and home. Their physical condition seems to make their lives difficult because most of them are called names, ridiculed, beaten and humiliated publicly, and rejected by both teachers and other peers who are different from them. The beliefs of the society in general appear to be leading these minority groups to see themselves as a misfit or outcast, avoided by their peers who sometimes refuse to sit, eat, or play with them and this puts pupils with the condition at a disadvantaged. It is from this background that this study was conducted to investigate the challenges pupils with albinism face in schools in selected schools in Zambia.

## II. METHODOLOGY

This study was qualitative in nature and Interviews and Focus group discussions were used to collect data. It was a case study which comprised of thirty (30) participants from St. Mary's Girls Secondary School and St. Mary's Special School for the Visually Impaired in Kawambwa. A descriptive research design was used. Twenty (30) pupils with albinism were sampled. The study implored a purposive sampling procedure in assigning participants for the study, that is, pupils with albinism. The interview schedule and focus group guide were used to collect data. Permission was sought from the school administrations as this study was conducted during school time. Data was analysed using thematic analysis.

## III. RESULTS

This study was exclusively devoted to finding out the challenges pupils with albinism face in schools. To this effect, focus group discussions and interviews were conducted to collect data. When the participants were asked to state the challenges, the following themes emerged; Some peers and teachers have a discriminative attitude towards the albinos and, some teaching and learning materials were not

user friendly.

### (a) Discrimination

On discrimination, the following were their responses;

*"They insult me and call me all sorts of names."*

*"Am likened to a ghost when at night by friends and this makes me feel as if am not a person."*

*"When am playing netball with my peers, they usually don't pass me the ball."*

*"Some pupils don't share their things with me, even food stuffs or sharing a bed."*

*"I usually don't report the discriminatory remarks which my friends have towards me to teachers because they don't pay attention to what I tell them. At times, they accuse me of being trouble some even when am not wrong."*

*"It hates me when derogative remarks are directed on me such that I cry because the pain becomes too much to bear."*

When asked to comment on the attitudes of teachers towards them, some pupils (18) with albinism indicated that they felt accepted by their teachers, especially those in the special school as shown from the following excerpts:

*"Teachers treat us with respect just like other pupils."*

*"...teachers in this school take care of us."*

On the other hand, some pupils (10) indicated that some teachers had a negative attitudes towards them. This is what some pupils said:

*"Some teachers saw us as a burden especially when I complained that I did not see if I well on the board. When I was at a Special School at Junior, teachers used to show us love..."*

*"We are meant to work during sunlight. They do not consider our condition."*

*"...their comments (teachers) sometimes made me feel as if I am not a normal and worthy person,"*

However, when asked to comment on the attitudes of their family members just to get a general picture on albinism, the majority of the pupils with albinism indicated that they feel comfortable in their families. They reported that their family members and their relatives accept their condition and loved them unconditionally. This was attested by their responses:

*"Everybody in my family understands my condition"*

*"My family loves me very much."*

### b. Lack of user friendly teaching and learning materials

When asked to comment on educational challenges, most of

them reported on what goes on in the classroom. They reported that they had difficulties looking on the white paper and on the board unless they moved closer. Further, they also indicated that they faced challenges when doing classroom assignments due to little time that they are given of which pupils without albinism found it easier to work it out on time as compared to them. This makes them to lag behind during class. This is what one pupil who was interviewed said:

*“I sit in front of the class closer to the board so that I can see what is being written on it.”*

Another albino had this to say:

*“I have problems with color identification such that during science subjects practical, am deceived into writing the wrong answer because the color I would see is not actually the correct one. This makes me to get low marks.”*

The issue of sight also came out prominently during the Focus Group Discussions. One pupil had this to say:

*“Tears come out of my eyes when I look on the white paper.”*

Another one had this to say:

*“I don’t see on the board and as such, I don’t answer questions in class because I can hardly see the writings on the white paper and the board.”*

Another pupil had this to say:

*“I usually forget what am taught and is even becomes worse when I go to the dormitory because I find it difficult to read what is on white paper. So I tell my friends to read for me but when they are not around, then I suffer.”*

Another issue which came out during the interviews was that pupils with albinism were in most cases discouraged by their peers who were not albinos especially during lessons. This is what one pupil with albinism said:

*“When am pointed by the teacher to answer a question, my peers shun me down by passing silly comments which are not pleasant. This discourages me to fully participate in class.”*

#### IV. DISCUSSION

##### (a) Discrimination

With regards to pupil’s perceptions and attitudes towards pupils with albinism, the findings revealed that their peers who were not albinos did not accept them. These findings are in line with Lund’s findings where teenagers with the condition were avoided by their peers who refused to sit, eat, or play with them (Lund, 2001). This was seen as an unhealthy attitude (Gaigher, Lund and Makuya, 2002) and denied these albinos an interactional opportunity which could boost their self-esteem. Such unpleasant remarks lead them to develop a tendency of isolating themselves and as such, their self-esteem seems to be gradually eroded in their developmental process. Crooker, Cornell and Major (1993)

contend that traumatised learners with albinism possess some attributes, or that convey a social identity that is devalued in a social context, hence stigma discriminatory attitude with albinism that are often perceived as people with low calibre. According to Magasu, Muleya and Mweemba (2020), a positive school climate has a positive impact on a wide array of outcomes for learners ranging from academic achievement to personal character. Attitudes are critical in inclusive education policy which Zambia adopted in 1996 (MoE, 1996). This was Zambia’s first commitment to equitable, quality and inclusive education. UNESCO (2005), defines inclusive education as a process of addressing and responding to the delivery of needs of all learners through increasing participation in learning, cultures and communities, and reducing exclusion within and from education. This means that albinos are entitled to the same range of educational opportunities and experiences as their peers who were not albinos.

Similarly, the findings have shown that parents and family members accept them and love them unconditionally. This makes them to feel comfortable in their families. These findings are supported by Hewitt (1991) who asserts that self-esteem in children is built by warm, positive parenting which makes them feel accepted as competent and worthwhile individuals. However, the current study is in disagreement with Machipisa’s (2002) report where he mentioned that the birth of a child born with albinism often caused conflicts in families, and sometimes led the fathers to reject the child or abandon their families.

Further, the findings of the study revealed that pupils with albinism received warm treatment from the teachers in the special school as compared to regular schools. When elaborating on the warm treatment, they indicated that unlike teachers in the mainstream schools, those in the special school understand their condition. These results concur with the findings by Gaigher, Lund and Makuya (2002), where special schools were rated high by participants with Ocular Cutaneous Albinism. These schools were preferred because special adaptations were made to the classrooms, and the teachers were aware of the participants’ visual impairment. The findings further indicate that a special school is also preferred because it encourages and supports positive attitudes towards albinism.

Furthermore, on the challenges faced by pupils with albinism, the findings showed that stigma and discrimination from both pupils and some teachers was the major challenge which they faced. Discrimination is believed to be one of the key manifestations of stigmatization. These findings have been attested by Small (1998) where she argues that in general, albinism is equated with, and categorized as a blemish, mark, stain, even disfigurement. Unlike any other stigma, albinism is the only condition of any type mistaken for mixed race. People with albinism are also perceived to be inscrutable, sinister, less capable or having a character flaw. Such remarks leads to pupils with albinism to develop a

diminished personality. Like any other human being, individuals with albinism accept themselves to the extent that they are accepted by others; their self-esteem is closely related to the approval of others (Konarska, 2005). By implication, the negative attitude by others can be a significant barrier to the learning process.

#### b. Unfriendly Teaching and Learning Process

The findings further revealed that pupils with albinism faced challenges in the learning process. Pupils with albinism reported that they often suffer from teasing and bullying from classmates. In some cases, they are unable to see the blackboard or white paper owing to significant vision impairment and such scenarios forces them to drop out of school. These findings have been supported by Lund's study on the health and education of children and young people with albinism in Zimbabwe (Lund, 2001).

These challenges disrupt the smooth learning of these pupils such that their performance in academics was poor as compared to pupils without the condition. The research findings have showed that the constant derogative attacks from the people around them coupled with difficulties in seeing on the board and the white paper have contributed to their lack of concentration in school thus performing poor in academics. These findings concur with Lund and Lynch's study on the outcomes of Special Educational Needs. Their study revealed that children with albinism were not attending school due to bullying by peers, lack of understanding from teachers or insufficient parental support (Lund and Lynch, 2011).

### V. CONCLUSION

Albinism is a condition which has a lot of negative aspects attached to it. Such negativity tend to be difficulty to manage thus pupils with albinism are often met with challenging situations which demands an assertive and positive personality character. Therefore, pupils with albinism needs acceptance and unconditional regard so as to enable them develop a positive self-image which in turn could give them courage and develop determination to pursue their academic endeavors and achieve great things. With the major challenge of stigma and discrimination being the order of the day, pupils with albinism need a warm environment from both teachers, peers and family members so that they can reach their full potentials in both curricular and extra-curricular activities in schools.

### VI. EDUCATION IMPLICATION

- Albinos will need compensatory academic skills-these are the skills that will make them learn better and benefit from education. For example, the use of large print materials such as font 14 and upwards will make them see the written letters and words clearly especially those with low vision. Some of them can use braille for those who may become blind.

- They will need to be advised by educators to wear optic devices such as spectacles this is because the condition of albinism may make them have refractive error of being either short or long sighted.
- They need to be orientated by sighted people in the new environment especially those who might be blind. Mobility is the ability skill of moving safely and independently in the environment. This is important to those learners with albinism who might become blind. They will need to be trained on how to move safely and independently
- They need to be taught the independent living skills or the daily activities such as socialization or meeting people and talk to them because they usually isolate themselves. Socialization is helpful to them because most of the things they will learn them through socialization from fellow learners such as academic work, use of money and business skills.
- Pupils with albinism should be allowed to wear caps in order to protect themselves from too much light and sunrays which usually burn their skin especially when they are doing outdoor activities such gardening, physical education and sweeping the surrounding.
- Educators should reduce the amount of light entering the classroom in order to reduce the amount of direct sunlight entering the room and hence reduce glare which may affect their vision and make them not see written letters and words clearly.

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