

Understanding the Lives of Student with Albinism and Technology Solutions in Schools

¹Muhammad Mansur Shehu & ²Aminu Aliyu

¹*Department of Psychology and Counselling
Adamu Augie College of Education, Argungu, Kebbi State.*
²*Department of Curriculum and Instruction
Adamu Augie College of Education, Argungu, Kebbi State*

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Abstract

It is obvious that students with albinism confront a lot of challenges in school despite their right to education and how society perceives them. In this paper, problems associated with students with albinism particularly their eyes and skin have been discussed. The study also discussed strategies for the protection of students with albinism, special education, and promoting their health and for African political economy and confronting emerging development challenges. Though, albinism is an inherited condition with high prevalence in populations throughout Africa and Nigeria in particular, what is the family perspective with regards to children with albinism since they are extremely sensitive to the damaging effect of the sun on their skin? The impact or challenges of albinism are particularly serious in areas that associate albinism with myth and tradition which leads to stigmatization and discrimination in the school and even society in general. The paper also discussed conflicts of rights and the right to their education. The conclusion was made whereby, society as a whole must become aware that stigmas and negative attitudes have a significant effect on the social, emotional, and psychological aspects of children with albinism's quality of life. Therefore, through this framework, it was concluded that students with albinism need to be supported particularly with technological devices, and by giving appropriate counseling intervention that could improve their psycho-emotional well-being and emerging development challenges.

Corresponding Author:

Muhammad Mansur Shehu

Background to the Study

Originating from the word “albus”, meaning white in Latin, albinism is a genetic disorder resulting in a decline or absence of pigmentation in the hair, eyes, and skin (Hong, 2006). For this reason, a student born with the genetically inherited condition of albinism are strikingly different from their peers. Instead of the usual dark pigmentation, they lack melanin pigment in their skin, hair, and eyes, making their hair sandy colored, their eyes blue to hazel, and their pale skin extremely receptive to the damaging effects of the Sun (Lund, 2005). Yahalom (2012), recently perceived as less obvious are the eye problems associated with albinism: involuntary nystagmus causing their eyes to wobble involuntarily from side to side, photophobia, poor depth perception, strabismus, poor visual acuity, and refractive errors. Baker, (2010) observed that albinism is a condition that results from a genetic mutation characterized by hypo-pigmentation of the skin, eyes, and hair. However, research conducted by Oetting (1996), shows that albinism includes a group of inherited disorders of melanin synthesis that affect the hair, skin, and eyes, which prevents the students with albinism from accessing their education like other normal students in the class. Those affected have pale cream to chalky colored skin, grey or hazel eyes, and sandy to yellow colored hair – a striking contrast in appearance when compared with normal dark pigmentation. This difference in appearance creates socialization and adaptation problems also in school for students with albinism. While a student with albinism has little protective melanin pigment, their skin is extremely sensitive to sunburn, skin lesions, and cancers, especially within Nigeria and the rest of African Countries (Kromberg et. al., 1989; Lookingbill et. al., 1995). Besides, the lack of pigment results in misrouting of the optic nerve fibers during development leading to lifelong visual problems (Biswas and Lloyd, 1999). Most students with albinism are born to normally pigmented parents. A study in South Africa found that eighty-five percent (85%) of the children with albinism had less than thirty percent (30%) vision, even with the best optical correction (Raliavhegwa, 2001). To date, there are a small number of studies concerning the life of students with albinism and their experiences (Pooe-Moneymore, 2012). Considerably, the understanding and perceptions of students with albinism are underexplored and little is known about their psycho-social issues. Limited understanding of their lives in the Nigerian context and lack of attention given to the particular needs of this group of students means that interventions to better support, empower, and protect them remain elusive. This shows that the very visible difference in appearance of students living with albinism can lead to a lack of acceptance and poor social integration. A myriad of myths and superstitions around the condition led to stigmatization, rejection, and a lack of understanding about albinism. Munyere (2004), described his understanding of living with albinism as he observed it as a 'disability that others do not understand'.

Family Perspectives

Families are the beliefs that God has wanted it to be or having some infections in the womb which made the baby white. This issue of infections or disease was raised by families on several occasions. There is even the anxiety that the condition could passed from a person with albinism to a normally pigmented person if a non-albino pregnant

woman comes into close contact with or looks at a person with albinism. Conversely, some families consider the birth of a child with albinism to be a gift from God or the will of God in a positive sense. They can hold this view despite the momentous negative and sometimes violent reaction they received from their own family, particularly the immediate members such as their husband or partner, but also from their community. Lastly, published data on the predominance of albinism among school students, indicates that there are a large number of people living with albinism in Tanzania that precisely outnumbered those from Nigeria, (Lund, 1996; Lund and Gaigher, 2002). It was critical that this paper could provide insight into giving equal opportunity and voice to children with albinism, their families as well and teachers who give counseling to these students in schools for their educational and social events that impact strongly and negatively on the mental and social well-being of these students with albinism. Like any other human being, students with albinism accept themselves to the extent that they are accepted by others since their self-esteem is closely related to the approval of others (Konorska, 2005).

Albino and their Challenges

Throughout Nigeria and Africa in general, an indeterminate number of students with albinism, especially children, have been the victims of brutal attacks and murder in the name of witchcraft, superstition, and wealth. The atrocities committed against albinos have received widespread attention because of various crimes reported, such as kidnapping, infanticide, amputations, and decapitations, that are committed to supplying highly valued body parts of these albinos that are used for amulets, which are then sold in underground witchcraft markets (IFRC, 2009). Therefore, Albinus lived in constant challenges of guilt and angst often forced to flee their homes and lived in solitude to avoid the albino huntsman that seems to be the major challenges they are facing. The main driving forces underlying these profiling crimes are ignorance, myth, and superstitions, such as the belief that individuals with albinism possess superpowers or that their parts bestow fortune and health (Aquaron, 2009). Thus, the stigma and atrocities affecting the albino population may be credited to a lack of awareness and education concerning albinism together with ignorance. Although, the National Organization for Albinism and Hypo-pigmentation (NOAH) (2017), points out that 'students with albinism always have vision problems that are not correctable with eyeglasses and many have low vision therefore, provision of suitable sunscreens and protective clothing should be effective in increasing protection and reducing the risk of skin cancer (Stern et al., 1986). However, the myths around albinism also play an important role in poor self-esteem and social incompetence in students with albinism.

Teasing and name-calling because of the different colors of their skin by other students and community members causes students with albinism to hate school. Lund and Lynch (2012) observed and identified that students with albinism who were not attending school, or if they started attending, are eventually dropping out. Among the reasons was the lack of adaptation of the educational system to take into account their visual impairment, rejection, and bullying from their peers and the lack of parental support and teachers counseling contributes to the major causes. The reflective effects of these

challenges, on students with albinism and the wider society, are how family members are forced to escort their children to school and other areas of the society.

A study also shows an account of parents hiding their albino at home, seeking asylum in police stations, or moving to safer parts of the country. Some families send their students with albinos away to boarding schools or to their relatives in safer areas (Burke, 2014). Such attention has also raised alertness to the need to address the challenges facing students with albinism, including stigma and the lack of access to education and health services (Burke, 2014). Some studies have emphasized the complexities some students with albinism face in developing relationships because of discrimination and stigma (Lund, 2001), especially the importance of acceptance by a partner's family and friends (Lund, 1998). In addition, the isolation of students with albinism can be confounded by the obstacles they face to being able to play outside with other normal students and to take part in outdoor activities at school at the same time being remaining safe from the damaging effects of the sun. Raising awareness through schools' curricula might help promote integration, although challenging, given that albinism is steeped in superstition and misconceptions that lead to fear and misunderstanding (Lund, 2005). Albinos and parents of albino students must understand the causes of albinism, as there are many medical and psycho-social implications, and how to properly guard themselves to develop the chances of survival.

Conflicts and Right to Education

In Africa and Nigeria in particular, was faced with meaningful barriers both to being and to doing, but there is less evidence on how these barriers should be overcome. It can be argued that many of the rights of students with albinism are not being enacted or put into consideration. It was argued that the government response in Nigeria to the killing of people with albinism, including increased segregation of students with albinism, has resulted in trade-offs between competing rights, potentially causing further harm to victims and families. People with albinism face real complexity when the right to life and protection can simultaneously lead to the loss of other freedoms and rights, such as family life, engagement in the community, or freedom of movement. These students with albinism should have leverage resources and action to promote protection and ensure the right to social justice. Separation for whatever motive, breaches the fundamental rights to leading independent, fulfilling lives, accessing education and work and ultimately developing relationships within local communities (Yahalom, et al., 2012). Although there are mixed policies on the education of students with albinism in Nigeria, many students with albinism experience a range of educational experiences. Sometimes they are educated in specialist schools for visually impaired students, although there is an escalating move to adopt inclusive education (Dogbe J, et al, 2016). Therefore, student with albinism have a right to education, hence attention needs to be given to them to ensure that their needs are met within a typical setting. This can sometimes mean only slight acceptance of classroom set-up, such as access to visual supports, but perhaps more fundamentally requires a modification in attitudes among teachers and other students.

Furthermore, myths and superstitions, fuelled by a lack of understanding surrounding albinism and the visible difference in the appearance of students with albinism can lead to stigmatization, rejection, lack of acceptance, perceptions of difference, and limited social integration (Pooe-Moneymore, et al., 2012; Brocco, 2016 and Bucaro, 2010). Their visible difference is so stark that they are in effect viewed as white people within a black community. Research conducted by Bucaro (2010) points out some of the cultural superstitions whereby the issues faced by students with albinism are seen to be a result of a curse, or they are seen as 'omens of disaster'. In addition, Brocco (2016), highlights the negative labels and terminology used to describe and define students with albinism. Mothers of students with albinism are often blamed for their child's condition and accused of unfaithfulness with white people carriers or spirits (Wan, 2003). Thus, many children with albinism are raised without the understanding and support of parents, creating financial difficulties and an inability to afford appropriate counseling and education for their child (Bucaro, 2010). But the hard work of many NGOs aims to offer this support. If well-informed, teachers can be a significant and efficient route for spreading information about counseling and encouragement, especially as they are such highly respected members of the community (Lund, 1998). In other world perspectives, recent anthropological research has critiqued the media for their simplistic approach of blaming traditional superstitions for the killings of people with albinism, identifying that contract killers are fulfilling a market demand for body parts for use as charms thought to bring wealth and good fortune (Burke, 2014).

There are strong arguments that it is poverty that drives the violence toward students with albinism (Bucaro, 2010), and this is specifically acknowledged by the United Nations as a key contributor to witchcraft-related violence (UN, 2017). Though poverty in and of itself does not cause violence in terms of students with albinism it seems to be a significant risk factor. Thus, teachers could provide counseling intervention with adoption in the classroom to reduce glare, with shutters on the windows at one side and a covered walkway on the other. The class should be equipped with a mobile blackboard on wheels that could be moved around to the best position at different times. The student with albinism should be allowed to walk up to the board to read. All these measures helped to alleviate the poor vision and extreme sensitivity to sunlight experienced by children with albinism. Therefore, access to suitable educational support, including teachers with the knowledge of how to assist children with albinism has been recognized as important in enhancing the self-esteem of these children, promoting their personal development and growth, and creating a sense of belonging (PooeMoneymore, 2012).

Therefore, mothers of newborn with albinism must fully understand the cause before coming back home from the hospital, because members of the family and society may presume that the infant is of uncertain ancestry, resulting in disapproval of the mother and rejection of the child (Lund, 1996). Their teachers must be informed that children with albinism are as capable as other students, but have difficulties with vision and reading, thus requiring enlarged text, textbooks, and seating closer to the blackboard (Simona, 2004).

Technological Perspectives as a way forward

Generally, technological devices serve to help students with albinism while facilitating their academic activities in terms of the learning process. Unfortunately, there are shortage and lack of these devices such as Lenses or binoculars, which are essential for students with albinism to assess prints on the chalkboard or assist learners with visual challenges since they struggle to see what is in normal printed books and what is written on the chalkboard. It was observed that even if they sat in front of the classroom, they felt uncomfortable using the hand-held lenses as they were too small to use for reading. Thus, according to Lanbon, (2021) and Osei-Antwi, (2015), suggested that using Technological devices will enhance teaching and learning for learners with low vision. Technological equipment such as digital tablets, optical character recognition (OCR), screen readers, Braille translation software, Braille writing equipment, closed-circuit television (CCTV), Braille embossers, scanners, Books with large prints for students with albinism and vision impairment. If appropriately used can enhance teaching and learning to the student with albinism.

Conclusion

Understanding the lives of children with albinism, particularly from their perspectives and within a social-relational paradigm of disability, is severely lacking in accurate research. This paper concluded that both children with albinism and their families experience a range of challenges and myths that impact strongly and negatively on their mental and social well-being which made them feel weak or caused anxiety. It also provides an understanding of the children with albinism via promoting their needs and a comprehensive, whole-school approach to issues such as superstition, sun protection, kidnapping, infanticide, amputations, and decapitation of family members and society in general. Their condition and needs are being enacted or deprived whereby inadequate provisions for students with albinism are not included in the designed Curriculum. Their voice concerning how they might be better supported and appropriate counseling, empowered, and protected has to date been deprived of. Exploring what is understood about students with albinism within an incorporated disability and needs can help to identify difficulties and challenges faced by students with albinism and suggest possible ways to overcome them.

Therefore, to better meet the many psycho-social needs of students with albinism in Nigeria, awareness and counseling interventions must continue to gain support. Society as a whole must become conscious that stigmas and negative attitudes have significant consequences on the social, academic activities, emotional, and psychological aspects of students with albinism excellence of living. Hence, technological equipment such as digital tablets, optical character recognition (OCR), screen readers, Braille translation software, Braille writing equipment, closed-circuit television (CCTV), Braille embossers, scanners, Books with large prints for students with albinism and vision impairment. If appropriately used can enhance teaching and learning to the student with albinism.

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