

Albinism: Implications of Marginalization on Education

Kazeem A. Badrudeen

University of Calgary

Here is the final project. Which I did considerably better. These two documents illustrates my progression in writing.

Abstract

Albinism is a unique genetic condition that results in the lack of pigmentation, causing affected individuals to have a pale skin. As a result of this condition, individuals with albinism often have some degree of visual impairment. Despite several efforts to bring awareness to this condition, research suggests that there is little known about it (Wan, 2003, p. 1). Historically, as a result of lack of awareness, these individuals face stigmatization, segregation, and rejection within various societies. Particularly in certain African countries, this condition is considered a work of evil. In these societies, people with albinism are killed, and their body parts are used for rituals (Wan, 2003, p. 2). Given these historical injustices, this paper examined myths surrounding albinism, the implications of marginalization, and the quality of education afforded to people with albinism. It was found that, despite efforts from many stakeholders in providing adequate education for people with albinism, people with albinism are still largely marginalized and segregated in specialized schools.

Albinism: Implications of Marginalization on Education

Albinism is understood as a genetic condition characterized by partial or complete lack of pigmentation in the eyes, hair, and skin. In addition to the phenotypic features associated with the condition, individuals with albinism are recognized as having various forms of visual impairment including photophobia, nystagmus, and myopia. Today, as a result of misconceptions, myths, and economic and political disempowerment, individuals with albinism in several sub-Saharan African countries face stigmatization and discrimination. In this paper, I aimed to examine the implications of these factors on the quality of education afforded to these vulnerable group.

Background of the Issue

The prevalence of albinism in the world today remains unknown; however, some researchers have suggested that it ranges between 1 in 70,000 and 1 in 90,000. Furthermore, research has also pointed out that the prevalence of the condition is higher in certain countries. For example, in certain African countries, albinism exists in 1 in 17000 people (Barnicot, 1953). Additionally, Africa seems to have a larger population of people with albinism than any other part of the world.

Around the world, albinism is hardly understood as a result of the assumptions and stereotypes that exist about the condition. In certain countries in Africa, people with albinism are less understood as a result of colour differences. Historically, albinism was considered a punishment for parents' sins, as a result, children with albinism were killed upon delivered. Similarly, mothers of people with albinism were thought to be sick and remedies need to be provided. To some extent, this perception still holds today. According to Mswela and Nöthling-

Slabbert (2013), when a label becomes part of an individual's description, there inevitably exists a problem in the sense that discrimination often germinates about that type of condition. Furthermore, the researchers pointed out that for people with albinism, their skin condition creates negative social constructs within African countries. There exists a perception that individuals with albinism are to remain in hiding, otherwise they will be killed. Additionally, Mswela, and Nöthling-Slabbert (2013) noted that these preconceived notions not only apply to their skin condition but also to their race. As such, there should be efforts amongst African governments to protect the rights of those afflicted with albinism to life, liberty, and the pursuit of happiness.

Community Practice Implications¹

Self-Perceptions

Given the historical injustices and the present day realities of people with albinism in Africa, it is critical to understand the implications of community practice on the quality of education afforded these individuals. It is particularly important to understand the social factors that results in the segregation of pupils in school settings. Lund and Gaigher (2002) noted that students with albinism were concerned regarding their lack of awareness on albinism. Furthermore, seventy percent of their participants noted that their parents failed to explain their condition to them (p. 368). Perhaps, this was as a result of their lack of knowledge about the condition themselves. Furthermore, some students suggestions that their condition was caused by a witch doctor further indicated their lack of understand about the condition (p. 368). Interestingly, Lund and Gaigher (2002) found that parents were more likely to hold positive perceptions of people with albinism's intelligence level than students (370). These findings

suggest that individuals with albinism have very little understanding of their condition, causing negative self-perceptions.

Social Interaction

As a result of the negative perceptions held by society about albinism, some parents are fearful of sending their children to school, thinking they might be attacked. Similarly, Gaigher, Lund, and Makuya (2002) pointed out that children with albinism are more likely to be isolated from regular activities such as playing with friends and interacting with cognitively challenging tasks, leading to lower levels of cognitive stimulation. Additionally, children with albinism felt unsafe around typical children (black children), and their poor vision served as an exclusionary measure from participation in activities with their peers (p. 5). Furthermore, children with albinism experience hostile interactions with their peers. Black children are unable to comprehend why people with albinism look different. As a result, lack of comprehension results in physical altercations between children with albinism and black children. Evidently, the visual impairment and differences in appearance of those with albinism hinder their social interactions, leading to lower levels of social adaptation.

Infrastructural Implications

Firstly, in most African countries, there exist three types of educational systems: the state controlled schools, federally controlled schools, and privately controlled schools. In addition to these schools, some private and public schools do exist to provide 'specialized' education to people with albinism. For the most part, all of these educational settings provide education to people with albinism, regardless of the color of their skin. However, many of the schools people with albinism attend are public schools, given the lower socio-economic status of these groups. In Africa's public education system, overcrowding is one of the major issues (Deininger, 2003, p.

300). For example, in Nigeria, there is a teacher student ratio of one to nine-hundred, whereas in private schools, the ratio is about one to forty. This inequality results in poorer education level for people with albinism and their further devaluation within society.

Secondly, to address the health related issues associated with albinism, some African schools have adapted their school environments to meet the needs of people with albinism. For example, in some schools, researchers have observed the planting of trees to provide shades and the placement of shutters on windows to help prevent glare. The prevention of glare is important for further impairment of vision for people with albinism (Lund and Gaigher, 2002, p. 369). These adaptations are some of the recent measure being adopted to address the risks of health related issues associated with albinism. In hindsight, the prioritization of appropriate educational infrastructures has not been a widely observed outcome. In fact, a majority of the schools attended by people with albinism are located either outside in the sun or under dilapidated infrastructures that do not provide conducive environments for learning (Haihambo, & Lightfoot, 2010, p. 77). These realities are a testament to the further marginalization and exclusion of people with albinism in schools.

Lastly, while specialized educational settings do exist, their capacities to provide education to large numbers of people are limited. Given the low level of funding in public education, many educational institutions are forced to find creative ways to address the implications. In many cases, this means fundraising to cover additional costs. Furthermore, while many African countries are moving towards a more inclusive education, the lack of financial resources allocated to schools poses challenges for addressing infrastructure challenges (Lightfoot, 2003, p. 24). The provision of more schools dedicated to ensuring that people with albinism's disadvantages are taken into account is important.

Implications of Access to Resources

Firstly, many children with albinism have detailed their experiences in terms of practices employed by teachers. On many occasions, children with albinism have complained about receiving poorer levels of education compared to their peers. In fact, many felt that they did not receive any education at all. Given these assumptions, I was interested to understand why this is the case; why people with albinism felt they are receiving poorer level of education than their peers. Firstly, as discussed earlier, the overcrowding of classrooms is a major issue in many African countries. This lead to less personalized time spent with each individual student by teachers. Secondly, there exists little training for teachers working with people with albinism. As a result, many teachers are unaware of how to accommodate the needs of people with albinism. Instead of addressing these issues, teachers often express the need for these students to be taught in specialized classrooms (Wan, 2003, p. 281).

Secondly, as a result of low levels of funding for public schools, the ability for schools to purchase things like assistive devices is a major challenge. One might wonder why families do not provide when the schools cannot. As stated earlier, as a result of the historical marginalization of people with albinism, both economically and politically, their abilities to afford things like magnifying glasses, identification canes, and lamps are very limited. These challenges pose major risks to the overall educational development of people with albinism (Braathen, & Ingstad, 2006, p. 290).

Thirdly, for those who are able to afford the devices, accessing trained professionals to educate their children on how to use the equipment is very rare. A majority of orientation and mobility specialists that exist are in the major cities, making those services inaccessible to those

living in rural areas. In many cases, this means traveling for very long periods of time to access these resources, and even then, the quality of services offered is very poor when compared to similar resources in developed countries. These challenges related to providing adequate services are very alarming (Braathen, & Ingstad, 2006, p. 290).

Policy Implications and practice

The implications of public and educational policies on the provision of adequate and appropriate education for all cannot be overemphasized. According to Polat (2011), as a result of cultural, political, and economic factors, even adequate public policies may not necessarily lead to accessible education for people with albinism. Polat pointed out that inadequate policies are one of the major challenges that prevent the equal access to education of people with albinism. While having resources to address the issues is important, it is more important to address issues around cultural practices, values, and attitudes.

Similarly, Haihambo and Lightfoot (2010) point out that, although the government in Namibia set up a national policy to address the issues affecting people with albinism, the researchers' participants noted that the society still operated from a medical model. Haihambo and Lightfoot (2010) added that, despite sensitization about albinism, the society still functions from a medical model perspective. Furthermore, sensitization campaigns have not been effective as a result of a lack of proper consideration about how perception of the conditions influence the way society responds to them. The researchers argued that, in order for any policy to be effective, it must understand the nuances of the condition within the family context.

Relatively, individuals with albinism must be considered as the major stakeholders in any policy that aims to address injustices and promote more accessible and equitable educational systems for them. Their understand of the condition and their expertise must be employed in the

process of drafting policies that will be effective in addressing the educational needs of people with albinism. Through collaboration and empowerment the relevancy of policies become more apparent (Lightfoot, 2003, p. 22-24).

As pointed out by Braathen and Ingstad (2006), In Africa, there are differences between those with and without disabilities. People with albinism are economically, politically, and educationally poorer than those without a disability. Organizations set up to address the challenges facing people with albinism are poorly funded; consequently, their effectiveness has been dismal (p. 603). The ineffectiveness of organizations aiming to advance the plights of people with albinism in Africa serve as reminders of the relatively low funding allocated by governments for addressing issues of people with disabilities in Africa.

To address this issue, Deininger (2003) suggested that reducing educational fees for primary education, the decentralization of schools, and the mobilization of local resources are effective strategies that need to be considered to address the cumbersome problem of funding for education. These strategies will increase the accessibility of education for people who have been historically disadvantaged by the system.

Conclusion

In this paper, I examined the implications of myths, misconception, and economic disempowerment on the quality of education afforded to people with albinism in Africa. Firstly, I found that children with albinism are disproportionately excluded from school, as a result of myths and misconceptions that exist in Africa about albinism. Secondly, as a result of infrastructural challenges, individuals with albinism are sent to specialized schools, where they are segregated and marginalized from society. Thirdly, as a result of a lack of access to proper resources, people with albinism are excluded from regular education. Lastly, as a result of

policies, or lack thereof, individuals with albinism are denied proper education. The combination of these challenges is a result of economic and political disempowerment. Africa has a moral and legal obligation to ensure that individuals with albinism are included in regular education and provided with appropriate resources to thrive and succeed.

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