

ALBINISM IN CAMEROON

How persons living with albinism experience social exclusion in Cameroon

MASTER'S THESIS

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<p>Abstract:</p> <p>This study aims to study persons living with albinism (PWA) experiences in Cameroon through the lens of social exclusion. PWA suffers from different forms of social exclusion in Cameroon because of the lack of Melanin. Studying their experiences with melanin people in Cameroon reveals that their lack of melanin (albinism) is a focal reason for their experiences of social exclusion. The difference in skin creates adaptation and socialisation problems, with many myths and misconceptions surrounding PWA that have spread over the years within many African Communities. They are viewed as ghosts and nonhuman by the melanin people who consider themselves humans. One of the main findings of this study is that albinism in Cameroon remains a misunderstood phenomenon, and many people do not understand the complex experiences of PWA in Cameroon. PWA continue to be ridiculed unconsciously due to a lack of knowledge of melanin people in Cameroon.</p> <p>This is a thesis summary of three blog posts focused on the issues of Albinism in Cameroon. This non-traditional thesis offers a novel way of conducting academic research. It is inspired by the article-based research style used in most PhD theses in Finland.</p>	
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To my beautiful daughter, Shanice. These years away from you have been one of the most challenging things for me. I hope you understand why I had to leave you behind for this. I love you very much.

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CHAPTER ONE

INTRODUCTION

This is a non-traditional master thesis. My thesis is written as a series of blog posts, and this is a summary of the thesis put together. Initially, I was interested in researching parents with children living with albinism. This is because I have two friends who are persons living with albinism or have a child with albinism. These friends have gone through a lot of stigma, discrimination and tagging because of how they look or have a kid with albinism. I remember back in the university when I met my friend Melissa (a person living with albinism). I was intrigued by how she looked, and I frequently asked her questions concerning her eyes and why she ate almost everything I ate, and her body still looked flawless. Growing up, we heard many stories (myths) concerning food people living with albinism shouldn't eat because some food will cause allergies. Melissa was going through a lot, not just how society looked at her but because her parents were also divorced when she was born, as her dad accused her mom of cheating and bearing three white skin children(children living with albinism). My roommate/best friend (Enaveline) in the university gave birth to a child with albinism, we were all shocked, and there was a lot of gossip about why she bore a white skin child when she and her husband were black skin. I was thinking about them while choosing my research topic. When I started writing, I contacted them to be connected to other mothers (participants). Still, it didn't end well because these mothers could not participate in the interview process because of the lack of internet connection in Cameroon. This lack of research participants made me change my topic and decided to do a blog post with some existing literature and materials.

My three blog posts focus on the general introduction and experiences of PWA in Cameroon through the story of one PWA (Melissa), an analysis of Facebook posts of melanised Cameroonian celebrities transformed into people living with albinism, and an analysis of a YouTube interview of two Cameroonian celebrities living with albinism.

1.1 Albinism

Albinism is an inherited condition that reduces or disables pigmentation in the eyes, skin, and hair because of the absence of melanin. This condition is usually characterised by pale/white skin, sandy coloured hair and light brown eyes. Persons [or a person] with albinism (PWA) or 'albinos' as they are more informally referred to, are naturally visually impaired and highly susceptible to skin cancer (King & Summers, 1988). At this juncture, it suffices to state that the most acceptable appellation in

plural form is ‘people/persons with albinism’, and a ‘person with albinism’ will suffice in the singular form. These phrases have been established to be most appropriate because they place the person’s humanity before the condition, whereas ‘albino’ is perceived as derogatory. ‘Albino’ is therefore deemed an unacceptable term because it de-personalizes the person, accentuates the condition rather than the person and adds to the stigma (Thuku, 2001).

In western societies with predominantly Caucasian populations, PWA often passes unnoticed; in sub-Saharan Africa, however, albinism is the most conspicuous of physical conditions, which makes it difficult for PWA to blend in, and therefore predisposes them to unwanted attention due to physical appearance and skin-colour difference (Baker, Lund, Nyathi, & Taylor, 2010).

1.2 PROBLEM STATEMENT

Albinism is an inherited condition; however, in most of Africa/Cameroon, people with albinism remain excluded from education and employment. Poverty and a lack of healthcare and social security structures further aggravate the situation, often putting the burden of care onto the family. As well as the practical problems associated with living with albinism in Cameroon, an enduring problem encountered by people with albinism is the stigmatisation and ostracism they face due to the web of myths surrounding the condition.

1.3 RESEARCH QUESTION

How do persons living with albinism experience social exclusion in Cameroon?

1.4 METHODOLOGY

This qualitative research describes the everyday experience of persons living with albinism in Cameroon. Denzin and Lincoln (1994) suggest that qualitative research examines things or

phenomena in their natural settings to make sense of them or understand them through the meaning that people give to them at a given time.

This study employs discourse analysis as the primary research method. Discourse analysis has been widely used in qualitative research. Discourse analysis refers to the study/organisation of language above the sentence or above the clause and, therefore, study of larger linguistic units, such as conversational exchanges or written texts (see Georgakopoulou 1997). It is also concerned with language use in social contexts, particularly with interaction or dialogue between speakers (see Frohmann 1994, Georgakopoulou 1997).

The following sections are Albinism and Albinism in Cameroon, Social Exclusion, Methodology, Results of the study, Conclusion and Discussion.

CHAPTER TWO

ALBINISM AND ALBINISM IN CAMEROON

2.1 ALBINISM

Albinism is a rare, non-contagious, genetically inherited condition that reduces the amount of melanin pigment formed in the skin, hair and eyes (Hong, Zeeb and Repacholi 2006). Albinism encompasses a group of inherited disorders of melanin synthesis, the pigment that protects the skin from ultraviolet (UV) light from the sun. Persons with albinism (PWA) may lack pigmentation in the skin, eyes, and hair, referred to as oculocutaneous albinism (Nasr 2010). Albinism occurs in all racial and ethnic groups worldwide (NOAH 2014, 1). Oculocutaneous albinism (OCA), which is very common in Cameroon, may cause visual impairment due to hypopigmentation of the iris and retina, hypoplastic fovea, hyperopia, strabismus, photophobia, loss of stereoscopic perception and nystagmus (Simona 2004). Due to the reduction or absence of melanin, PWA is highly susceptible to ultraviolet (UV) radiation's harmful effects and is at greater risk of actinic damage (Hong, Zeeb and Repacholi 2006).

2.2 Key Definitions

Persons with Albinism (PWA): Persons with albinism (PWA) are people (infants, children, youth and adults) with visible and or less obvious albinism traits. They are also called *albinos* (in Cameroon – Mukala), although many today find the later term untactful and somewhat disparaging social label for albinism victims.

Myth: The word myth is used most popularly in tales and stories. These tales and stories have been passed down from generation to generation and are based on some truth, but mostly an idea or common theme. Myths are stories that are based on tradition. Some may have factual origins, while others are entirely fictional. However, myths are more than mere stories, and they serve a more profound purpose in ancient and modern cultures.

Witchcraft is the practice of secretly using supernatural power for evil to harm others or to help oneself at the expense of others (Tebbe 2007). Witchcraft is deeply rooted in many African countries and communities in Sub-Saharan Africa. However, historically, witchcraft in Africa has not comprised a stable or uniform set of beliefs. Beliefs in witchcraft are beliefs in systems of power

derived from unseen forces. For those who believe in supernatural powers, those forces are pretty accurate and are not merely symbolic allusions to other phenomena.

Superstition is a belief that does not have an immediate empirical foundation in things or phenomena. Although owing their origin to perfectly natural and logical causes, they are attributed to some supernatural force or power, the results of which are distorted by popular imagination and fantasy (Mulemi 2004). Superstition can be understood as an attempt to seek and explain patterns in occurrences. Superstitions often occur in situations of uncontrolled uncertainty, where the reason for the link between occurrences is not well understood with a natural explanation.

Stigmatisation: Goffman (1963) first defined stigma as a physical or social attribute or sign that devalues an actor's identity and disqualifies the actor from full social acceptance. Stigma has its roots in 'differences', which can be related to personality, physical appearance, illness, disability, age, gender or sexuality (Mason et al., 2001). The pain and the emotional hurt that the stigmatised experience is directly connected to the pity, fear, disgust and disapproval of this difference expressed by other people (Mason et al., 2001). Hence, stigmatisation is a social process created by people out of fear of the disease by contrasting those who are 'normal' to those who are 'different'. Stigma includes three components: problems of knowledge (ignorance and misinformation), issues of attitudes (prejudice and perceptions), and problems of behaviour (discrimination and physical attacks).

Discriminations, stigma and attacks on people with albinism are particularly frequent in sub-Saharan Africa because of myths surrounding their nature. PWA in these regions are often avoided by their communities and viewed as non-human spirits or ghosts; some believe that minerals contained within PWA body parts bring wealth and luck, leading to the dismembering and killing of many PWA, including infants and children. Stigma has its roots in perceived 'differences', and it triggers pain and emotional hurt linked to others' pity, fear, disgust and disapproval of this difference (Mason et al. 2001). Stigma suffered by PWA generally affects them irrespective of gender, ability, age, gender or sexuality. Discrimination and prejudice suffered by PWA separate and exclude them from society and many of its benefits, such as equitable access to resources and services like housing, education, health and social support.

2.3 Albinism Myths and Misconceptions in Africa

The passing of time has bestowed various modifications on people's perception of albinism. These perceptions are rooted in the works of some philosophers and how their expedition across Africa was instrumental in disseminating ideas on albinism (Sandford, Thomson & Cunningham, 1841). Given that these philosophers, some of whom were actively involved in the colonisation of African regions, were regarded as highly scholarly and enlightened, their ideas and theories were deemed sacrosanct, undebatable and acceptable (Malcolmson, 2016). African natives felt the need to ground albinism in cultural beliefs to explain those acquired ideas and perceptions. The consequences of these beliefs about albinism are manifested through labelling mechanisms, such as name-calling and social marginalisation.

The difference in skin creates adaptation and socialisation problems, with many myths and misconceptions surrounding PWA that have spread over the years within many African Communities (Scheen 2009). In most Sub-Saharan African countries like Zimbabwe, Ghana, Tanzania and Cameroon, there is a strong belief in the connection between Albinism and witchcraft.

In light of this, albinism is believed to bring good health, financial and material wealth, cure HIV/AIDS, and appease the mountain gods when a volcano erupts (Roura et al. 2010). In addition, the study by Deborah et al. (2010) in Tanzania revealed that miners use the bones of persons with albinism as amulets or bury them where they are drilling for gold and that fishers weave the hair of persons with albinism into their nets to improve their catches. The above mentioned are only beneficial to people who think body parts of PWA bring luck while putting the lives of PWA in danger as they are hunted and killed.

Furthermore, studies conducted by Bieker (2006) and Braathen and Ingstad (2006) in Tanzania and Malawi, respectively, reported that people with albinism are perceived as ghosts and cannot die but instead disappear, which is why they are perceived as mysterious and dangerous beings.

In Ghana, Benyah (2017) observe that in Ghana, some communities, e.g. Atebubu, the Brong Ahafo Region and families believe that giving birth to a PWA is a misfortune. Thus, Benyah (2017) observes that attempts are made to kill the PWA or abandon or banish these PWA children at birth.

In other African countries, it is believed that “albinos body parts could help politicians win elections and businessmen become fantastically rich overnight, and could cure infertility and ward off evil spirits” (Gifford 2015, 15).

The above-cited myths reported across Africa imply that stigmatisation of people with albinism is still widespread in the region despite the United Nations Human Rights Council and the African Commission on Human and Peoples’ Rights adopted resolutions calling for the prevention of attacks and discrimination against persons with albinism. These different cases and reactions to albinism in other African countries are very similar to Cameroon’s case.

2.4 Albinism in Cameroon.

In the Fali community of the North, albinism is understood as a curse that could afflict the rest of the family. Therefore, many Fali with albinism are killed at birth to stop the curse from affecting the entire family or end the curse (see Djantou 2009). In the Bamileke tribe (Western province of Cameroon), those with albinism are often thought of as spiritual beings, ancestors or ghosts with supernatural powers. The birth of a child with albinism is seen as a punishment for the misbehaviour or misdeeds of the parents (Djantou 2009).

Many believe that the sacrifice of people with albinism can offer protection from or appease the mountain god - Epassa Moto (Sinior 2006). Some people with albinism were abandoned on Fako Mountain as offerings. For example, people with albinism are fearful when the volcano becomes active. It is common knowledge that during such times, PWA relocates and stays away from the region until after the eruption.

In the Betis tribe of the Centre Province, there are reports that charms are made from the hair and fingernails of people with albinism (Yemeli 2015). Here, some believe those with albinism never die. As a result, charms made from their body parts are potent and will never fail.

Women and girls with albinism in Cameroon are often targets of sexual violence. According to OHCHR (2013), common myths associated with albinism include “sexual intercourse with a woman or a girl with albinism can cure HIV/AIDS.” Girls with Albinism who have suffered from sexual violence have a compound traumatic experience, Post Traumatic Stress Disorder (PTSD), increased health vulnerability like pregnancy and Sexually Transmitted Infections (STIs). Other myths are that sex with a girl or woman with albinism can bring good luck.

The life of people living with Albinism in Cameroon is entrapped with difficulties. In all aspects of social, economic, and cultural life, children with albinism in Cameroon remain highly marginalised, stigmatised, and excluded because of their condition (see Djantou 2009). They remain vulnerable to violence and stay fearful. Despite all these difficulties, violence against children, girls and women with albinism in Cameroon is underreported. Many Cameroon albinism civil society groups suggest that more science-based explanations of albinism challenge the most powerful myths and associated incidences of violence. It remains to be seen if this science-based knowledge will be properly sensitised and accepted in Cameroon, especially in rural societies where traditional beliefs remain very strong. The adverse myths that affect people’s lives with Albinism in Cameroon have firm roots in religious beliefs (see Djantou 2009).

Albinism is still profoundly misunderstood in Cameroon and Africa as a whole. 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 (Benyah 2017). This leads to various forms of stigma and discrimination: Women who give birth to children with albinism are often repudiated by their husbands and their families because they are unaware that both parents must carry the gene to pass it on to their children. Further, children with albinism are frequently abandoned by their parents or, more sporadically, the victims of infanticide because of the appearance of their skin, the disabilities they may have as a result of their condition, and the belief that they may be a source of misfortune. The deeply entrenched prejudices they face worldwide also impede persons with albinism from accessing adequate health care, social services, legal protection, and redress for rights abuses. The forms of discrimination faced by persons with albinism are interrelated (see Benyah 2017). Their right to education, for instance, is affected by their vision impairment, which can force them to drop out of school. A poor level of education, in turn, can lead to unemployment and affect their right to an adequate standard of living (Benyah 2017)

CHAPTER THREE

SOCIAL EXCLUSION

Social exclusion is a process, not only the condition reflecting the outcome of that process (Silver 2007). According to Silver (2007), social exclusion is multifaceted and affects different people differently and those who belong to the margins get affected more than those in the centre. Social exclusion results include the failure to integrate some people into social, political, economic and cultural circles of what is considered the norm or centre in most communities/countries (Silver 2007).

The difficulty in conceptualising social exclusion lies primarily in the inability to apply any one definition of the concept universally. Parent and Lewis (2002) outline a few measurements that researchers on social exclusion have employed. However, research on the concept has repeatedly been shown to fall back on poverty indicators (Silver 2007). Meanwhile, there remains no agreement on which single indicators and methods can universally apply to measuring social exclusion (Parent and Lewis 2002; Popay et al. 2008). In her writing about the development of the concept, Silver, therefore, argues, “the difficulty in defining social exclusion makes it hard to measure” (Silver 2007, p.18). To this end, I will outline some definitions and indicators developed through research on social exclusion.

Since René Lenoir’s writings on *les exclus*, the literature and policy discussions around social exclusion have evolved from identifying groups at risk of being excluded and have grown to encompass a wide range of social and economic problems (Sen 2000). For example, Silver (1995) lists social categories from which people can be excluded, including the nation of the dominant race; family and sociability; permanent employment; earnings; and property, to list but a few. These indicators have contributed to defining social exclusion in many ways. For example, Walker and Walker have distinguished poverty and social exclusion (1997, cited in Levitas et al. 2007, p.21). The latter is a comprehensive formulation of the dynamic process of being excluded from full participation. Madanipour et al. (1998) define social exclusion as a multi-dimensional process consisting of various combined forms of exclusion that find a spatial manifestation in particular neighbourhoods. Room (2010) explains that the main appeal of social exclusion, and the subsequent shift from poverty, stemmed from its multi-dimensional and relational concern with dynamic processes in various contexts. Similarly, Silver (2007) emphasises that social exclusion is a process

that is dynamic, multi-dimensional, and context-dependent and is conventionally concerned with social relations between the active excluder that governs access to resources and the excluded. Berman and Phillips (2000) view social exclusion as a multi-faceted phenomenon that manifests itself at the macro (Demos/national) and the micro (Ethnos/community) levels. Popay et al. (2008) define social exclusion as a continuum of inclusion/exclusion. This dynamic, multi-dimensional process is characterised by unequal power relations across four dimensions (political, social, economic, and cultural). They distinguish between social exclusion as an ontological state –commonly described in policy contexts – and a multi-dimensional process. Levitas et al. (2007) additionally explore the concept of ‘deep exclusion’, defined as “exclusion across more than one domain or dimension of disadvantage, resulting in severe negative consequences for the quality of life, well-being and future life chances” (p.9). One critique of social exclusion theory is that it is “a broad screen, a curtain which [hides] problems of desperate destitution” (Gore and Figueiredo 1997, p.44, cited in Popay et al. 2008, p.44). Popay et al. (2008) counter this argument by referencing Amartya Sen (2000), who emphasises that social exclusion rests in its forceful emphasis on the role of the relational features in capability deprivations. Despite the numerous available definitions of social exclusion, there is a common understanding that it is dynamic, relational, context-dependent, multi-dimensional, and multi-faceted. These aspects of the concept distinguish it from poverty (Levitas et al. 2007).

3.1 Social Exclusion from a multidimensional perspective and relational perspective

Social exclusion is a multidimensional, dynamic and relational concept (see Room 1992, 1995).

3.1.1 Multidimensional Perspective of Social Exclusion

Social exclusion is multidimensional and can encompass a lack of access to employment, legal redress and markets; a lack of political voice; and poor social relationships (see Beall and Piron 2005, Levitas 2006). Put differently, “social exclusion is multidimensional: it encompasses social, political, cultural and economic dimensions, and operates at various social levels” (Khan et al. 2015, 3). The multidimensionality of social exclusion encompasses social, political, cultural and economic dimensions, operating at different social levels.

3.1.2 Relational Perspective of Social Exclusion

The social exclusion relational perspective looks at unequal power relations in social interactions. It can produce ruptures in relationships between people and society, which result in a lack of social participation, inadequate social protection, lack of social integration and lack of power (see Khan et al. 2015). “The relational aspects of social exclusion also unfold dynamically. The relationships in which a person is involved today may have implications for their capacity to manage relationships in subsequent phases of life. The causal links between, for example, health and low income must be analysed within a relational context as they unfold over time (dynamic)” (Room 1999, 171). In all, the social exclusion relational perspective has two dimensions. On the one hand, it focuses on exclusion as the rupture of relationships between people and the society resulting in a lack of social participation, social protection, social integration, and power. Alternatively, a relational perspective points to exclusion as the product of unequal social relationships characterised by differential power, i.e. the development of the way societies are organised (see Mathieson et al., 2008)

3.1.3 Dynamic Perspective of Social Exclusion

This refers to social exclusion's changing and interactive nature along different dimensions and varying levels. Room (1995) contends that persistence over time is an integral aspect of social exclusion, while others (Levitas et al., 2007) have argued that judgements about the importance of persistence are neither theoretically nor empirically based. Most definitions recognise that the experience of social exclusion is unequally distributed across socio-economic and ethnic groups and that it is not a static state always experienced by the same social groups in all places. The dynamic perspective of social exclusion forces us to study social exclusion in different ways to differing degrees at different social levels over time.

CHAPTER FOUR

METHODOLOGY

4.1 Qualitative research method and Discourse Analysis

This qualitative study investigates the human perception of a given phenomenon (Albinism). Thus, this study focuses on understanding present human relations and making recommendations for future human relations and interaction. Denzin and Lincoln (1994) suggest that qualitative research examines things or phenomena in their natural settings to make sense of them or understand them through the meaning that people give to them at any given time. Denzin and Lincoln (1994) observe that qualitative research approaches the world as a unique feature of human interaction in which individual discourses reflect group ideologies. Thus, understanding the ideologies of a group requires understanding various discourses – how and why they are constructed in the way they are in a given society. It is for this reason that Qualitative researchers claim that the experiences of people are essentially context-bound; that is, they cannot be free from time and location or the mind of the human actor.

This study is rooted in a qualitative research tradition (Denzin and Lincoln 1994)). This study aims to study PWA's experiences in Cameroon through the lens of social exclusion. This study employs discourse analysis as the primary research method. Discourse analysis has been widely used in qualitative research. Discourse analysis refers to the study/organisation of language above the sentence or above the clause and, therefore, study larger linguistic units, such as conversational exchanges or written texts (see Georgakopoulou 1997). It is also concerned with language use in social contexts, particularly with interaction or dialogue between speakers (see Frohmann 1994, Georgakopoulou 1997). In this study, I engage discourse analysis as a way of approaching and thinking about a problem providing a definite answer to problems based on scientific research and enabling us to understand the conditions behind a specific problem and make us realise the essence of that problem, and its resolution (Fairclough 2003 Frohmann 1994). Put differently, discourse analysis in this study provides a basic methodology to describe and analyse how the structure and content of the text-encode ideas and the relationships among the ideas themselves are systematically present in the text (Fairclough 2003, Hamuddin, 2012).

Discourses refer to our constructing knowledge about a particular topic or practice; a cluster (or formation) of ideas, images and practices that provide ways of talking about forms of knowledge and

conduct associated with a particular topic, social activity of institutional site in society. Halls 1997, 4)

Discourse in this thesis expands from just written texts and spoken text to meaning embedded in images (see Hall 1997 and van Dijk 2000). In the context of this research, different actors on Facebook interpret or respond to a selected picture of “albinised” melanin people’s picture on Facebook and how PWA discusses the issue of albinism in Cameroon. Using discourse analysis, I could try to answer questions like why create a series of pictures where melanin people are presented as Albinised people? Why is such a presentation fascinating to melanin people and offensive to people with Albinism? How do people living with Albinism in Cameroon talk about their Abinism with melanin people? Would the discourse be different if they talked to a group of people living with Albinism?

Discourse analysis can be divided into two major approaches: language-in-use (or socially situated text and talk) and sociopolitical (see van Dijk 2000; Moberg 2022). The language-in-use approach is concerned with the micro dimensions of language, grammatical structures, and how these features interplay within a social context. The sociopolitical approach looks at the macro dimension paying attention to the context and power structures that produce specific discourse.

To be more specific, I employ the multimodal approach to discourse analysis. Multimodal discourse analytical approaches regard the text as just one of the many modes of communication available for social interaction. Multimodal discourse analysis refers to analysing various and different semiotic modes in a discourse. It aims to integrate the representational, interactive and textual meanings achieved by various elements. Its task is to analyse how these elements work together to form a complete discourse. As a matter of fact, in current writing, the textual structure is realised not only by linguistic signs but also by layout, colour, and typography both at the level of “clause” and at the level of “discourse” (Wei, 2015). There is a widespread belief now that textual data is not necessarily the most critical mode used to construct and interpret social meaning. The use of written text, images and speech that make up the collective data for this thesis accounts for why multimodal discourse analysis worked well.

For each case study, I started by defining the research question and selecting the content for analysis. I proceeded to gather information and theory. I analysed the content for themes and patterns, reviewed the results, and drew conclusions.

4.2 Methodological breakdown of the research by blogs

Blogs	Data	Methodology	Social Exclusion perspectives
Blog 1: Introduction to Albinism in Cameroon	Review of existing literature on Albinism.	Literature review	<ul style="list-style-type: none"> •Albinism in Cameroon •Introduction of the experiences of PWA in Cameroon through the story of one PWA.
Blog 2 Albinism is more than just a white face	Facebook post	Discourse analysis (Fairclough 2003 Frohmann 1994)	<ul style="list-style-type: none"> •Relationality approach. • Experiences of PWA compared to melanin people captured in Facebook photo series.
Blog 3 I am black and proud	<p>Youtube interview of two PWA in Cameroon 36minutes interview</p> <p>The data were transcribed and analysed around the question How does PWA experience social exclusion in Cameroon? What are some of the solutions to these identified from the perspective of PWA</p>	Discourse analysis (Fairclough 2003 Frohmann 1994)	<ul style="list-style-type: none"> •Multidimensionality approach •Different ways in which PWA suffer from social exclusion in Cameroon

4.3 Summary of the Blog post

Blog 1: Introduces readers to the concept of albinism in Cameroon. In this blog, I introduced the experiences of PWA in Cameroon through the story of one PWA on a YouTube video. This blog sets the tone for the other blogs in this series.

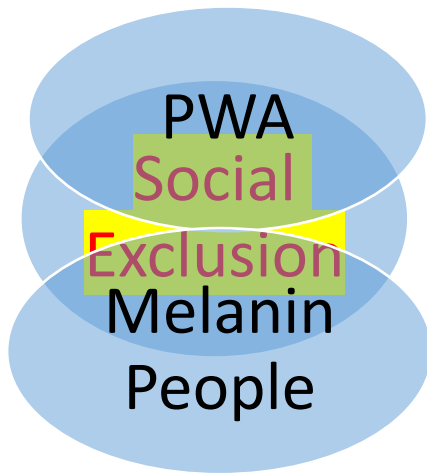
Blog 2: In blog 2, I study a series of pictures published on Facebook. This picture portrays melanin people as if they were people living with albinism. It also displays a person living with albinism as a melanin person. The aim of such portrayal is unclear. I have reached out to the author of the pictures for comments but have not received any reply. This Facebook post introduced exciting discourse on the issue of PWA. It is important to note that while some people were fascinated by this, other Facebook users warned that such a presentation does not help people with albinism. In this blog, I argue that such a presentation can be very counterproductive to the course of PWA because it does not consider the lived experiences of people living with albinism. Albinism is more than looks. People living with albinism suffer from social exclusion, which is not captured in the picture. It is essential to raise awareness of PWA's predicament rather than use what makes them socially excluded as an assessable fun characteristic. For example, the use of blackface by whites in Europe has been heavily criticised because blackface hides the racial experiences of blacks in Europe.

Blog 3: In blog 3, I analyse a YouTube interview of two Cameroon PWA artists on world Albinism day. These two PWA discuss various issues relating to albinism in Cameroon. In this blog post, people living with albinism are analysed using the social exclusion multidimensional lens. For example, their experiences regarding healthcare difficulties, education, and religious and social constraints are discussed. I argue in this blog that these experiences need to be understood, and solutions need to be investigated and put in place for PWA in Cameroon. In this blog, PWA provides information on their predicament and some possible solutions.

CHAPTER FIVE

SOCIAL EXCLUSION AND ALBINISM IN CAMEROON

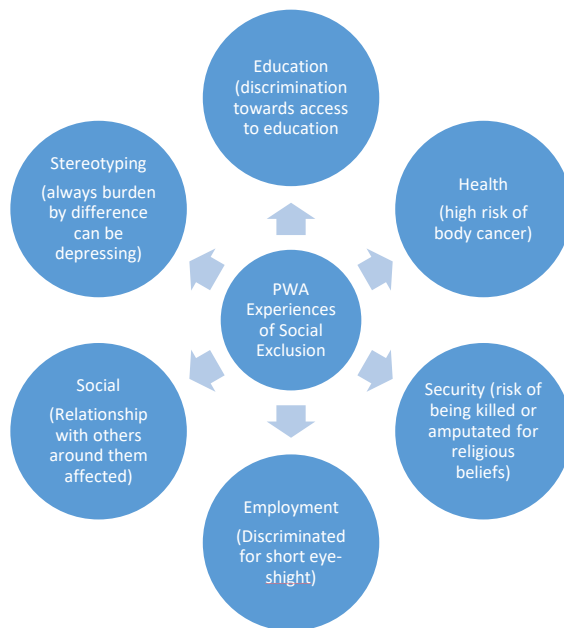
5.1 Social exclusion and albinism in Cameroon: A Rationality perspective



Here the main point to note is that PWA suffers from different forms of social exclusion in Cameroon because of the lack of Melanin. Studying their experiences with melanin people in Cameroon reveals that their lack of melanin (albinism) is a focal reason for their experiences of social exclusion. They are viewed as ghosts and nonhuman by the melanin people who consider themselves humans. Blog 2 highlights this when Mr Adrenaline's Facebook fun series shows the lack of understanding of different forms of social exclusion experienced by PWA and melanin people in Cameroon.

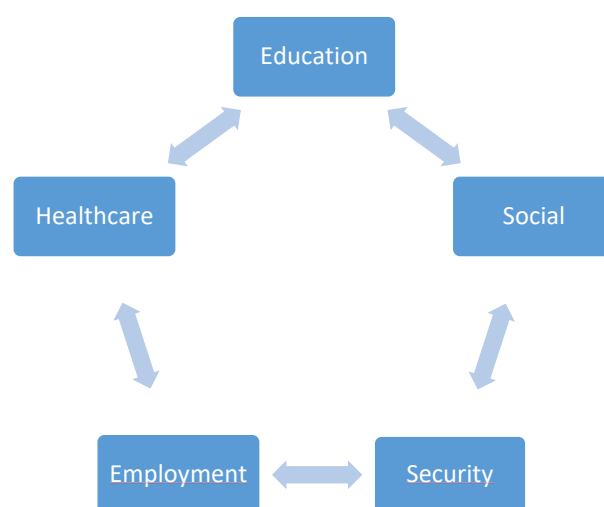
5.2 Social exclusion and albinism in Cameroon: A Multidimensionality perspective

Multidimensionality looks into the different facets through which PWA experience social exclusion. This study shows (see blog 3) that PWA in Cameroon suffers from social exclusion, ranging from education, employment, social, healthcare, etc.



5.3 Social exclusion and albinism in Cameroon: A Dynamic perspective

The experiences of PWA cannot be viewed or understood in isolation. Their experiences are dynamic in the sense that they are interlinked. For example, because of poor health conditions, PWA may not have access to schools, and because of lack of education, they may not have easy access to employment. On the other hand, PWA may not have access to education because of security reasons, and other forms of social exclusion will follow. See the figure below.



In all, it is essential to note that social exclusion in this study provides a critical lens to study the experiences of PWA in Cameroon. This thesis highlights how this can be done and recognises the need for more research along these lines. I started this study to study mothers' experiences of children with albinism. Although I could not carry out that exact study due to a lack of collaboration from the mothers in Cameroon, I still believe this is an important area for future research.

CHAPTER SIX

MAIN FINDINGS, CONCLUSION AND RECOMMENDATION

6.1 MAIN FINDINGS

Albinism in Cameroon is a significant problem and can be studied from a social exclusion lens. Albinism in Cameroon remains a misunderstood phenomenon. Many people do not understand the complex experiences of PWA in Cameroon. PWA continue to be ridiculed unconsciously due to a lack of knowledge of melanin people in Cameroon.

PWA in Cameroon suffers from multiple forms of social exclusion, including healthcare, employment, security, etc. PWA continue to be stereotyped in the media as they are only cast in stereotyping roles. Children with albinism experience a great deal of bullying due to their physical appearance. This bullying can easily lead to intense feelings of being unattractive or left out. To help children with albinism at school, parents, students, and teachers should work together to create individualised educational plans, including larger print sizes, preferential classroom seating, and computers for students with impaired vision. Participation in a peer support group can also help kids with albinism to improve their emotional health. PWA need more positive attention because they are human like the other melanin people in Cameroon.

PWA believe that their social exclusion experiences in Cameroon are dynamic and need interruptions through positive sensitisation about albinism in Cameroon. The lack of awareness about albinism in Cameroon is the problem, not people with albinism. More awareness is a need in the healthcare sector, religious sector and general public knowledge.

6.2 RECOMMENDATIONS

First, the entirety of this thesis has been written in simple language so that its content can be comprehensibly accessible to people in academia. This is because at the core of this project lies a necessity for society to address issues of social inequities and the consequent injustices and inequalities for PWA. They happen to be disempowered by the unfair configuration of Cameroon. Seemingly, if they are to be effective and efficient in their delivery and sustenance, the necessary interventions would require interdisciplinary and multi-sector collaboration between the learned society, socio-political lawmakers and policy drivers, and custodians of socio-cultural values and practices. It is envisaged that the findings and recommendations drawn from this study would inspire a culture of reciprocal duty of kindness and equitable care in line with humanity that entreats everyone

to be kind, respectful and considerate of one another (Mugumbate & Nyanguru, 2013; Nussbaum, 2003).

PWA has always been a part of Cameroonian society, even though the transactional configurations of the society continue to pose limitations to their social mobility and, by extension, their social wellbeing. In its literal sense, being different connotes a sense of distinction but in a way that segregates, marginalises and disadvantages PWA, as is the case in this study. This constitutes moral and ethical implications for Cameroonian society as a whole. The responsibility of blame has to be shared by everyday members of the society and those at the helm of power across all social institutions. Fundamentally, the willful (or unintended) injustices that PWA experience in formal social institutions such as in school and the working environment are suggestive of the lack of compliance to the Commonwealth's core values of human rights; concern for the vulnerable; and inclusiveness that a member nation such as Cameroon is expected to embrace (Foreign and Commonwealth Office, 2013). Consequently, this can be attributable to the Government's poor vigilance in monitoring and ensuring compliance of these social institutions to the stipulations of good governance.

Given that visual impairment is the first limitation for PWA right from birth, even before they become integrated into society, I contend that providing accessible [or affordable] eye care services from an early stage would significantly increase their visual capacity. This responsibility rests on the Government to recognise albinism as a disability and pull the necessary economic levers of equity that will ensure medical and social welfare for babies with albinism during the developmental stages of growth. This interventional approach can achieve equality of accessing full learning participation for children with albinism alongside other children in the schooling environment during childhood and, by extension, increase their capability for self-determination to access social goods throughout their life course.

6.3 CONCLUSION

These results may not reflect the life of all PWA in Cameroon. However, it is vital as part of an essential discourse on this subject that must not be underestimated. More research on PWA is needed not only in the context of Cameroon but also in other African contexts. People living with Albinism

are a socially excluded group in Cameroon, and more needs to be done by the government and others in the society.

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APPENDIX 1

BLOG 1

When White Looking is viewed as a curse.

Whiteness is the centre of the world¹. Although Cameroon is a black-dominated country, proximity to white gives one more advantage. For example, in some tribes like the Bameleki in the western province, fairer (whiter) women fetch a higher bride price than darker women. Skin lightening products are top-rated as people constantly seek fairer skin tone to attract the advantages associated with being white. However, there exist some groups of Cameroonians who were born “white”. One would think they would hail kings and queens and shower them with love and admiration. On the contrary, they are shunned, despised and even hunted. Herein lies the contradiction that is the life of people with albinism in Cameroon.

Albinism is a word derived from the Latin *albus*, meaning white. It's a genetically inherited condition where a shortage of melanin pigment affects the eyes, hair and skin². This condition affects the body's melanin production, reducing or eliminating pigmentation in the skin, eyes, and hair. This melanin deficiency causes complex visual impairment, altering retinal development and nerve connections to

¹ See Alemanji, A.A (2016). (2016). Is there such a thing...? A study of antiracism education in Finland. University of Helsinki.

² See Benyah, F. (2017). Equally Able, Differently Looking: Discrimination and Physical Violence against Persons with Albinism in Ghana. *Journal for the Study of Religion* 30,1(2017)161-188

the eye³. It also weakens natural defences against sun damage, placing people with albinism at heightened risk of skin cancer, especially in hot countries. The difference in skin creates adaptation and socialisation problems, with many myths and misconceptions surrounding PWA that have spread over the years within many African communities.

In Cameroon and other African countries, people living with albinism are given negative pseudo names, and subjected to stigma and prejudice because there are prevailing myths and superstitious beliefs about them not being humans.

Testimony by my friend Melissa Longla.....[VOICES OF ALBINOS 2 - YouTube](#)⁴

³ See Benyah, F. (2017). Equally Able, Differently Looking: Discrimination and Physical Violence against Persons with Albinism in Ghana. *Journal for the Study of Religion* 30,1(2017)161-188

⁴ [VOICES OF ALBINOS 2 - YouTube](#)



Melissa Longla, in her interview on YouTube, says human relations as a person with albinism have been pretty difficult.

"People make fun of your person. Some think you're a curse or product of adultery and negative things. Children chant derogatory songs while you walk past the streets, and people wouldn't eat food touched by you.... You have to survive amidst all these," she explains.

One incident which particularly hurt Melissa was back in secondary school when her classmate refused to eat just because she was the one who shared the food at the refectory. *"This really*

⁵ Picture of Melissa and I

weighed down on me," she laments.

"Another incidence was when a boy in my class (form 1) cried all day because he was made to share a desk with me!" Apart from these, Melissa says job officers have severally turned her down because employers think people like her cannot fully deliver at work.

The life of people living with Albinism in Cameroon is entrapped with difficulties. In all aspects of social, economic and cultural life, children with albinism in Cameroon remain highly marginalised, stigmatised, and excluded. They remain vulnerable to violence and stay fearful. Despite all these difficulties, violence against children, girls and women with albinism in Cameroon is underreported.



⁶ The conversation. <https://theconversation.com/being-black-in-a-white-skin-students-with-albinism-battle-prejudice-78368>

Parents, especially mothers of people living with albinism, face stigma at the family and community level. Many women have been sent out of their marriages because their husbands could not understand why two black people could give birth to a white skin baby.

The plight of albinism needs to be brought to the lime. People with Albinism must not suffer just because they were born different in the same way black argues that it is unfair for the world to treat them as inferior because they were born black. Being a person with albinism is not a crime and criminalising them is criminal.

Share the word, share the awareness and share the love.

APPENDIX 2

BLOG 2

Albinism is more than just a white face.ⁱ

Living with Albinism in most sub-Saharan African countries is one of the most challenging things because of the negative attitude toward people with albinism. Albinism is a rare, non-contagious, genetically inherited condition that reduces the amount of melanin pigment formed in the skin, hair and/or eyes. Albinism encompasses a group of inherited disorders of melanin synthesis, the pigment that protects the skin from ultraviolet (UV) light from the sun.⁷

⁷ Nasr, S. L. (2010). How albinism works. <http://health.howstuffworks.com/skin-care/problems/medical/albinism.htm/printable>.

People constantly misunderstand people with Albinism and joke about their harrowing experiences. As a kid in Cameroon, we used to rally behind a person with albinism and sing derogatory songs. This was because we believed all the myths surrounding their existence.

On November 8 2021, Mr Adrenaline, a film director in Cameroon, shared 59 pictures of different Cameroonian celebrities on his official Facebook page ⁸with the caption, Tag the artist... fun time. The next day he shared 39 similar photos. In these pictures, Mr Adrenaline using picture editing software, transformed the looks of the melanised Cameroonian celebrities into people living with albinism. Some of the photos of this transformation are shared below.

No one knows if this is a campaign in solidarity with people living with Albinism or if it is a fun time, as the author of this post indicated. However, these pictures have provoked different kinds of discussion on Facebook.

He shared his picture with the caption *in an alternate reality*.

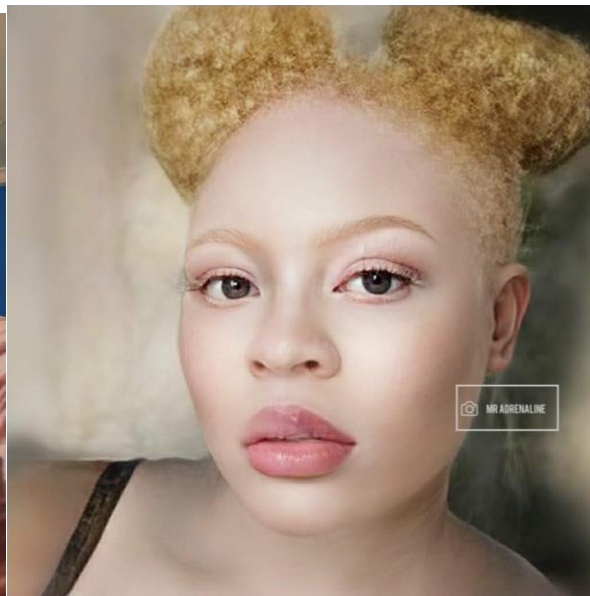
⁸ (https://m.facebook.com/story.php?story_fbid=432327028264143&id=100044605471761)

Mr. Adrenaline: Film director



9

ASKIA: Musician




10

⁹ Mr. Adrenaline: Film director

¹⁰ ASKIA: Musician

“New Look Pure Beauty, but I love my chocolate skin” (Facebook response by Askia in a post of this picture on her Facebook page on 11. 11. 2021.)

Askia’s post had some severe criticism by one of her Facebook followers. The Facebook follower called out Askia for appropriating albinism without ever raising awareness on the topic.



Askia dis might be funny for you, but i dont feel its funny, they re comments like oh she should remain dat way. I know you re a dark skin woman, but appropriating albinism without ever talking about the topic and how it affects ur fans who are of this community, i find it, insulting to them. Appropriation is not fun, its ignorance.

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There is a need for an intensive awareness campaign on albinism and the people living with this condition in Cameroon. Albinism is often a source of discrimination and sometimes fear-related violence. People living with albinism, easily spotted by their white skin and fair hair, have long been ostracised and discriminated against, especially in Cameroon. They are the target of superstitions and sorcery; they are hunted down for their body parts, some of which are thought to confer magical powers¹². Appropriating albinism for fun feels more like ridicule of the condition rather than creating awareness or solidarity.

As an artist, Askia is in a position in the Cameroon society where a majority could hear the population’s voice; her followers expected her to raise awareness with such a post rather than posting for fun. Colourism has a life-threatening dimension when persons with albinism are hunted, mutilated and killed because they are categorised as different and unique due to their fair skin colour.

¹¹ Facebook comment from Askia’s follower

¹² Benyah, F. (2017). Equally Able, Differently Looking: Discrimination and Physical Violence against Persons with Albinism in Ghana. *Journal for the Study of Religion* 30,1(2017)161-188

Response from a Person Living with Albinism

Boy Tag: Cameroon Musician. A person born with Albinism. Picture transformation to a melanised black person. He adopted his artist Name Boy Tag as empowering gesture of celebrating his Albinism. Growing up, he was always tagged as the odd and different boy because he was born with albinism. Adopting the name Boy Tag is empowering and political and disarms the slur in the mouths of those who only see him as a person living with Albinism.

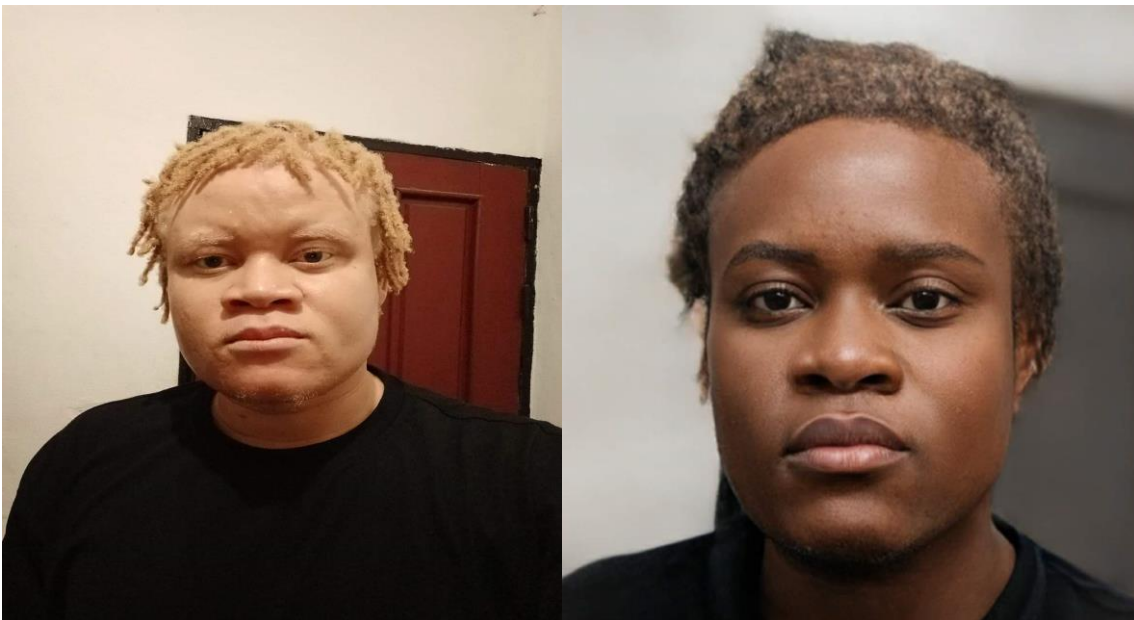
Boy Tag responded to this Facebook post by sharing a picture of himself (photo on the bottom left with the caption.

“No Filters”.

This is like saying, “here I am, albino and proud. I do not need filters to know I am beautiful and wonderfully made”.

The campaign’s author took the picture posted by Boy Tag and produced a filtered replica of Boy Tag in a black face. He posted the black-faced picture with a message....

Boy Tag Them don over request you. Na you that - Boy Tag, many people have requested that I design a picture of you. Here you are (my translation from pidgin to English).



Boy Tag

Selected response on the picture series on Facebook:

Some people viewed this as fun, just like the post’s author intended; some even requested their pictures be edited. Some people in the comment section though if all Africans were white skin like the author portrayed, the world would be easy for everyone (white makes things easy).



13

This blog brought out the agency of whiteness in black society. Colourism is discrimination based on skin tone, operating within or outside racial groups.¹⁴ The colourism that drives the skin-lightening industry is skin-tone discrimination that discriminates against dark skin due to social perceptions of fair skin as beautiful. Whiteness is understood as setting Africans with albinism apart from the norm of black Africa. Whiteness is linked to beliefs about albinism as strange and different, such as people with albinism being labelled as “ghosts”. Social meanings applied to albino skin are entirely different. If these pictures were made and shared on Albinism Day, it would have been easy to link these pictures to a sensitisation campaign about the plight of people living with Albinism in Cameroon. It could be a powerful message to remind everyone that anyone can and could have been a person living with Albinism. It would show people how they would look in an “alternative reality”.

¹³ Screenshot from Mr. Adrenaline post

¹⁴ Marira, T. and Mitra, P. (2013) Colorism: Ubiquitous yet understudied, *Industrial and Organizational Psychology*, Vol. 6 no 1. 103-107 DOI: 10.1111/iops.12018

There was no guided discourse on or about the plight of people living with albinism. There were many derogatory comments about people with albinism. The discourse generated on Facebook by this was more negative than positive. In all, this picture series can be considered counter-productive to the plight of people living with Albinism in Cameroon. It ridiculed their experiences because albinism is not just the colour of one's skin in a picture; it involves living with the fear of being killed. Living with a Tag as different in a negative way all of these leads to multiple layers of social Exclusion. Cameroon celebrities like Mr, Adrenaline need to be educated on the plight of people living with Albinism and the issues of racism. They should be using their platform to help spread kindness to PWA and sensitise the public on the plight of PWA, not just for fun.

APPENDIX 3

BLOG 3

I AM BLACK, PROUD and a Person Living with Albinism in Cameroon.

People living with albinism are viewed in Cameroon as a problem because of their white skin colour and their condition's myths. They exist and live their lives in a contradiction to the black racial identity of Cameroonians. Their skin colour attracts different myths, which causes physical and emotional hurt inflicted by their fellow black compatriot.

This is the view of two Cameroonian artists living with albinism – Mola Moombe and Don Chaeule. Mola is a musician, and Don is a standup comedian. They were interviewed on a talk show called freaky table on world albinism day 2021. The talk show lasted for 35minutes and aired on youtube on the 14th of June 2021, with the title; Black in white skin, exposing myths and stereotypes of albinism and hosted by Joan Ngomba. This is my analysis of the discussion raised in the talk show. Being different is a social problem and should be addressed with strategic interventions that target

the root cause(s) of the disadvantages and injustices PWA are subjected to in Cameroon. Attention must be turned to a model of disability that considers ‘disability’ as a social construction of how society uses an individual’s impairment to disrupt and disallow social engagement.



Myths about people with albinism

Don observes that

I have heard of people who still face a lot of stereotypical treatment, like young girls being sexually abused because they are believed to have powers to cure diseases.



Mola adds that

I must tell you that what made me stop shaving my hair is that those guys try to steal your hair on three different occasions when you go shave. I had to fight physically with one guy, and I beat him seriously; that's because when I left the saloon after shaving, my little nephew told me....Uncle, while that man was shaving your hair, put some in his pocket". I went back in and confronted the guy; then, he told me some women offered him money in return for the hair because they believed it could be used to get lucky charms. people still think our blood or some parts of our body has spiritual powers.



These myths about people living with albinism make these people's lives difficult. When people believe that one's body, hair or blood can be used in rituals to enhance their lives, it makes the body parts and blood of people living with albinism. The demand for the blood and body parts of people living with albinism exposes them to deadly and physical danger.

Mola adds that

Also, the myth about albinos living forever is a big lie. We do die. The world or people won't notice because not every family has an albino. Only those who are directly affected know when their albino family members die.

No one lives forever and albinos do die. People think PWA do not die because they believe people living with albinism are spirits, and spirits do not die.

Coming from Fako, an area in Cameroon with potent myths that people living with albinism are the perfect sacrificial subjects to appease the gods of the Fako Mountain (efassa moto), Mola observes that.....

I was made to understand that this myth of sacrificing albinos to the mountain gods came from the diversity in what/how people think that we are spiritually strong. Back then, those who brought the myth of sacrificing albinos to the mountain were fighting with the families who had albinos in their families. Since these people living with albinism were considered spiritually strong, those who didn't have albino came up with stories about albinos being cursed and sacrificing them to the mountain god will cleanse the land and the family.

It is interesting to note that the perceived strength of people living with albinism in most African countries is the source of the myth that they will be most suitable for sacrifice. However, according to Molar, it is essential to note that *“No one was ever seen being sacrificed to the gods”*.

Another myth about people living with albinism lies in what they should eat or cannot eat. This myth is debunked by Don when he argues that

I don't buy into that myth of not eating particular food because I am an albino. I eat everything, especially crayfish, which everyone says we should not eat.

Mola:

Being an albino, I have done a lot of research. I have brothers and friends who are doctors and ask many questions. Melanin has nothing to do with food or what we eat. We have a deficiency of melanin which is natural, not in the blood; our diet has nothing to do with it. I eat every food I like.

Source of these Myths.

Mola highlights that the sources of myths against people living with albinism come from stories passed down from generation to generation. These stories originated from a time when African religious beliefs were predominant. The truth lies in the stories handed down through generations in this time and context.

Mola highlights that

We have been told stories by our grandparents that if you are born into a house with an albino, it is believed that witchcraft cannot come to that house. Those stories I believe them because I am an African, there is some degree of spiritual strength, and just as we look different, spiritually we are different, it's true.

Myths tell us about the reality of the universe and all its components. In the context of African cultures, African myths explain significant human concerns and facts such as death, creation, the evolution of living things, man's relationship with other living creatures, etc. However, the purpose of a myth is far more than explanatory. It has many values in the African societal setting. It acts as a socialising agent. Mola is a believer in African myths/stories, and he has used the fact that he is different and spiritual as his shield.

Don argues that

It is true that we are Africans, and there are certain myths or beliefs that may die down due to civilisation depending on where you find yourself in Africa, and there are some that we can't really do anything about.

More information is needed to counter the myths about people living with albinism. Debunking these myths will help safeguard the life and safety of people living with albinism.

Don believes that the media has a big role in debunking these myths. He criticises the current position of the media.

The media is not helping though they are the touch light to help us see. A lot of people in the movie industry only cast PWA when they need someone for sacrifice. Persons with albinism are talented; they can be in lead roles..... give them a chance.

When the media only cast people with albinism to act in a role that reproduces myths about people living with albinism, the media serves to recycle existing myths. Don's recommendation that the media integrate people living with albinism into central roles and characters is essential in rebranding the image of people living with albinism. They have to be viewed as the norm rather than as abnormally.

Physical Challenges of people living with albinism

One of the challenges highlighted by Don is one of poor sight.

People assume there is a disability in albinism. To be honest, it's true because our eyes are not good. We might wear all these fashionable glasses, but we are still unable to see clearly. I don't think our skin has any issue because there are also people with dark skin who have some skin problems too.

Although people usually want to point at the skin of people living with albinism as a problem, this participant observes that his most significant issue is poor sight because dark skin people also have skin problems like people living with albinism.

Molar observes that

The only problem I think is that the lack of melanin makes our skin fragile, that's why you can't see me with short sleeves during the day while the sun is hot..... I want to live long, so I have to protect myself.

Awareness about one's self is central here. Molar acknowledges that the sun affects his fragile skin differently. As such, it influences what he wears. His skin is delicate because of a lack of melanin and living in a country with a lot of sunshine.

Mola argues that one of the biggest problems of people living with albinism is poverty and a lack of proper information.

I know a lot of albino struggle, and I think it's because of poverty; some parents do not know how to protect their albino children at an early stage. I see a lot of young kids living with albinism running under the sun without any hat to protect them from the sun, and it saddens my heart.

Poverty and lack of information affect the quality of life of people living with albinism. This is a problem that every person in Cameroon has.

I AM BLACK, PROUD and ALBINO

It is not every day that people living with albinism describe themselves as black, as many people do not see them as black because of their lack of melanin. People in Cameroon forget that these people are black because their skin colour is white.

Mola observes that.....

I am very proud of being black, and trust me being black is not only by pigment. My mom always told me, if they say....” you look different”, tell them.....” You all look the same”.



As Alemanji (2016) argues that whiteness is more than biological or physical appearance, blackness is not about physical appearance. People living with albinism in Cameroon are blacks. Their blackness is unique and must be celebrated.

Don observes

Be proud of who you are! Go there and do it better than the black people, the white people; you are better than anyone.

Albinism is thus perceived as a condition attributable to God’s will and therefore included among the multifaceted domain of reality. The idea that albinism is a physical condition determined by God was also voiced by Mola and Don when they said

“God created all people”.

References

Alemanji, A. A. (2016). Is there such a thing...? A study of antiracism education in Finland. University of Helsinki, Department of Teacher Education Research reports 400.

[Black in White Skin: Exposing Myths & Stereotypes of Albinism - YouTube](#)
