



EFFECTS OF STIGMATISATION ON PSYCHOSOCIAL AND HEALTH WELL-BEING OF PEOPLE LIVING WITH ALBINISM IN SOUTH-WEST NIGERIA

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ABSTRACT

People living with Albinism (PLWA), often referred to as Albinos are seen as very special people in many parts of Africa because of the colour of their skin and eye. Sunlight often exposes them to vision problems, sunburns and skin cancers. Albinism, a group of medical conditions arising from recessive genetic mutation causes the deficiency of a pigment known as melanin. Albinism is considered a disability and sufferers are often stigmatized. Descriptive research design was adopted using purposive sampling method to select 73 Albinos in Lagos, Nigeria. A self-structured questionnaire tagged (ESPHWPLWA) with a reliability coefficient of 0.82 was used as instrument for data collections. Analysis was done through descriptive statistics of frequency count and percentages and Pearson Product Moment Correlation. Hypotheses were tested at 0.05alpha level. Result showed a significant relationship between stigmatization and psychological well-being of albinos ($N = 73$, $r = 0.00$, p -value (1.00 , > 0.05)). However, the result revealed that stigmatization does not affect social well-being ($N = 73$, $r = 0.86$, p -value (0.02) < 0.05); and health well-being ($N = 73$, $r = 0.79$, p -value (-0.03) < 0.05) of albinos. It was concluded that stigmatization demoralises and devalues PLWA. The study recommends that ritual killings and stigmatization of PLWA must stop as a matter of urgency.

KEY TERMS: albinism, stigmatisation, health, psychosocial well-being

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INTRODUCTION

Many people in Africa are affected by albinism. The affected people with albinism in Africa stand out in stark contrast to those around them due to differences in color and living among the black people. Lund (2001) affirmed that their distinctive appearance has a powerful impact on their lives from birth to death. African report (2012) asserts that in some African countries, it is believed that albinos are a bad omen. Masanya, Mvena and Kayunze (2014) said the unique condition and distinctive appearance are surrounded by myths and stereotypes which have powerful negative impacts on their lives. In some communities, it is believed that having a baby with albinism is a result of bewitchment. In the same vein, it has been documented that in many developing countries such as Tanzania, persons with disabilities continue to be less valued, dehumanized and rejected principally for ritual purposes. Ritual killing of the albinos has been on the increase in Tanzania. Palmer (2007) affirms that people with albinism face discrimination and segregation and are often shunned by their families and communication like other people with disability.

In southwest Nigeria too, some indigenous movies titled: *Ti Oluwa Ni-Ile* – meaning: “God owns the Land” demonstrated the attempt to use an albino for rituals. With the case of Tanzania and that of Nigeria, it could be deduced that Albinos in any African country could be easily discriminated, dehumanized and devalued. It is further observed that albinos in Tanzania are no longer able to live normal lives due to constant fear of being murdered. In fact, it was reported that series of ritualistic murders forced people with albinism to request for police protection and refuge in places considered being safe. It could be expected that people with albinism in African countries have a very different life situation than people with albinism from countries where the majority of the population is Caucasian. The National Organization for Albinism and Hypopigmentation (NOAH) (2014) affirmed that more than 17,000 people in the United States have some type of albinism. Also in western and Caucasian countries, people with albinism do not stand out as much as they do in countries where the majority of the populations are black people. In this same vein, albinism is considered a disability and people with albinism often consider themselves to be disabled in many African countries. In the western world however, there is a controversy as to whether or not albinism is a disability up till date. It is needful to stress here that humans are not the only ones with disability of albinism. It is a condition which occurs in humans and other mammals. Famous among these are the white elephants in India which were honored at the king’s court or white tigers, Giraffes or lions which are highly appreciated by zoological gardens.

In the same vein, Medard (2009) found that, most people living with albinism are born to parents who have normal hair and eye color for their ethnic backgrounds. This could be explained pathologically. Because the body has two sets of genes (one from the mother and one from the father), a person may have normal pigmentation but carry the albinism gene. Also, if a person has one gene for normal pigmentation and one gene for albinism, he or she will have enough genetic information to make normal pigmentation. However, the albinism gene is ‘recessive’ which means that it does not result in albinism unless a person has two genes for albinism. The fact about albinism is, when both parent carry the gene and neither parents has albinism, there is a one-in-four chance at each pregnancy that the baby will be born with albinism. This type of inheritance is called “Autosomal Recessive Inheritance”.

Another major characteristic of the albinos is that most of them have serious vision difficulties. Their eyes do not have the fetal and infant stages of their life, this causes abnormal development of the macular hypoplasia (the fovea in the retina) as well as abnormal nerve connections between the brain and their eyes. In Africa, many people are affected by albinism characterized by the lack of pigmentation. Nigeria is one of the countries that have her own share of people living with albinism otherwise known as albinos. These white skinned people who are not Europeans but happen to be fathered and mothered by black parent have been subjects of discussion among people. In furtherance to the above, Yekeen (2010) confirms that people living with albinism are looked upon as bastards or products of evil that their parents have committed. It is also believed that, some quarters, albinos are products of sexual intercourse between couples who had sex in the day time. Albinos are called names on the streets and people stare at them making them feel as if they have been unfortunate to have come to this part of the world in such skin. In the same vein, people living with albinism are not given the chance to show how pleasant they are because they are only greeted from afar as if they are no human beings. Unfair remarks are also made about them such as “Eni Orisa” meaning “person of the gods”. This may not be unconnected with the valance that they are useful for money rituals and other various appeals to the gods. Some people also believe that albinos have unpleasant body odor, this being one of the reasons people shun or refuse to make friends with them. Stigmatization of the albinos is believed to have psychological, social and health effects culminating into withdrawal from the society.

BACKGROUND

Concept of albinism

The term albinism has been used to describe living creatures with albinism. They have little or no color in the skin, eyes and hair. Conceptually, Albinos are people like anybody else, but they live with a special condition called albinism. Medard (2007) posits that it is characterised by a deficit in the partial or complete absence of pigment in the skin, hair and eyes. Albinism is said to arise from recessive genetic mutation that causes the deficiency or absence of a pigmentation known as Melanin. There are two main forms of albinism. The first one is oculocutaneous and the second is ocular albinism. NOAH (2010) asserts that there are many types of albinism depending on the amount of Melanin in a person's eyes. Some people have the fabled red or violet colored eyes but most albinos have blue eyes while fewer albinos have haze, brown or grey eyes. These discrepancies between reality and the red-eyed albinos myth are the reason that most albinos do not even realize that they have a form of albinism. The Summers (2009) lists two most common types of albinism as first: oculocutaneous albinism (also known as type one albinism) or (tyrosinase-related albinism) which influences hair, skin and eye color. The second most common is called ocular albinism which influences mostly the eye, but the skin and hair may have slight discoloration.

The additional group (third group) is people with ocular albinism (OA) whose diagnosis may be delayed until later in life. Although, the ocular characterises albinism, the condition is marked by near-normal pigmentation in hair, skin and eyes (though there is no pigmentation in the retinas). Achie, Roy and Robin (2005) found that OA depicts the pattern of inheritance which varies from autosomal recessive gene and is 'X-Linked' meaning that this type of OA can be passed from mother carrying the gene to their sons who may have OA. Meanwhile, 'X-Linked' mean that, the OA gene is on the X chromosome. Females carrying the genes can often be identified through an eye examination. Nigeria being one of the most populous countries in Africa has its own share of the clinical conditions called albinism. People living with albinism in Nigeria have had to live with stigmatization and discrimination like every of their counterparts in other parts of the world especially Africa. It is also believed that numerous challenges continually confront millions of people living with albinism first as an individual and as a demographic group within the continent. Albinos are classified amongst the vulnerable groups in African societies including Nigeria. The prevalent rate of albinism in Nigeria is ranked amongst the highest in the world with estimated figure of over two millions albinos living in the country. By implication, the Albinos Foundation in Nigeria (2015) reports that people living with albinism (PWA) in Nigeria represents one of the largest vulnerable groups in the country today. However, despite their stated vulnerability and strength in number, and unlike other vulnerable groups in Nigeria, they least enjoy the same level of special attention, security and support from governments at all levels in the country.

The need for special attention to be given to the security and socio-economic well-being of all persons living with albinism and other vulnerable groups in Nigeria cannot be overemphasized because, specific areas of their life require prime focus and special intervention. Medard (2009) posits that identified areas requiring both governmental and societal intervention include healthcare, advocacy and social awareness, education, social inclusion, academic education, economic empowerment and socio-political protection from various forms of societal abuse and discrimination. Mmuso (2007) posits that poverty and lack of education suffered by albinos does not stem from any mental or physical disability but mostly as a result of discrimination, social exclusion and stigma and in some cases, the human rights abuse they suffer as a result of their skin color. The president of the albinos confirmed that statistics indicated that, more than 1.5million Nigerian albinos were among the poorest, least educated and marginalized, adding that these performs were also most susceptible to skin cancer due to frequent exposure of their skin to the sun. In this same trend, Zango (2011) reports that over 600,000 Nigerians living with albinism suffer discrimination from their families, school mates, and peers. It is not uncommon to find families practicing infanticide on babies born with albinism. There is deliberate neglect to education of children with albinism, believing that their employment chances are limited, and therefore, their education is considered a waste of resources. In the same vein, some families abandon newly born children with albinism. This cruel act results in an albino having a slim chance to make it in life with most parents reluctant to invest in the education of albino children.

Myth and misconception on albinism

In some part of Africa, the condition was traditionally thought of as "a curse" or as some form of "punishment" from the gods. Muthee (2011) found that children born with albinism have been natively killed immediately after birth by parents and midwives in some countries. Without enough information on the condition, parents' families and communities have been at pains to explain the condition when a child with albinism is born. It is no gain saying therefore, that myths about albinism continue to persist in many parts of Africa. Many women have been divorced by their husbands and shunned by family members after giving birth to children with albinism as if they have committed a crime. They have been accused of sleeping with men of other races; of being cursed and unclean;

and of being witches. Children with albinism have also been hidden from the public, forbidden from socializing with others and treated as outcasts.

Health wise, a person with albinism is prone to rapid sun burn. PLWA are highly sensitive to ultraviolet exposure and have to be very careful not to get sun-burn. This is because their skin could burn easily and are therefore at a very high risk of skin cancer. Allen (2011) reported that, they have significant impairment of their vision and can be very sensitive to bright light; this is known or called photosensitivity. PLWA have “low vision” and hold things up close to see them better. They are influenced by light, glare and distances; even with the interventions like glasses they still have difficulty distinguishing objects and or distances. Many of them squint their eyes and peer in order to see. Premise on all of the above, they tend to experience stress, discomfort, head ache or fatigue. Headaches are common among PLWA. This should be discussed with registered medical practitioner immediately. Headaches are said to be physical response to light and glare not simply stress and anxiety.

Wellbeing is understood as a state of health, happiness and or prosperity. World Health Organisation (2006) posits that the understanding of wellbeing is all about living a good life with which one is satisfied. It is most usefully thought of as the dynamic process that gives people a sense of how their lives are going through the interaction between their circumstances, activities and psychological resources or mental capital. Esther, Hojo and Michael (2006) also see it as a state of holistic health in all its dimensions: physical cognitive social emotional, social and spiritual. Wellbeing is a state of being with others, where human needs are met, where one can act meaningfully to pursue one’s goals, and where one enjoys a satisfactory quality of life. Wellbeing consists of the full range of what is good for a person. These include: participating in meaningful social role; feeling happy and hopeful; living according to good values, as locally defined; having positive social relations and a supportive environment; coping with challenges through the use of appropriate life skills and having security, protection and access to quality services. Mmuso (2007) further asserts that all of these would not be achieved when the PLWA are stigmatized and marginalized. Their psyche would be affected and moral values dampened. The fear of death has always been a serious issue among the albinos. While going into hiding for fear of being used for money rituals has always been the case in most African countries.

The problem

Numerous challenges continuously confront millions of people living with albinism in most African countries. Across African countries including Nigeria, albinos are classified amongst the highest in the world with estimated figure of over two million albinos living in the country. By implication, people living with albinos (PWA) in Nigeria represent one of the largest vulnerable groups in the country. In spite of their stated vulnerability and strength in number, and unlike other vulnerable groups, in Nigeria, they least enjoy the same level of special attention, security and support from government at all levels in the country. Albinism and its associated medical problems including what stigmatization does to people living with albinism have been a source of discussion by so many scholars in recent times, but not much has been done concerning how stigmatization affects the health and psychosocial well-being of people living with albinism. In most cases therefore, the negative attitude of the community was due to myths and superstitions about oculocutaneous albinism. Without doubts, this situation could result in low self-esteem, loneliness and isolation of the person. Isolation also increases the situation of the affected persons. This means that, they may not be able to access the essential services, such as health and educational facilities to meet their physical and developmental needs. Discrimination is believed to be one of the key manifestations of stigmatization. Discrimination is also said to have an insidious impact on the dignity and self-image and self-confidence. Poverty and lack of education are further problems suffered by the albinos. This does not stem from any mental or physical disability, but mostly as a result of discrimination, social exclusion and stigma, and in some cases, the human rights abuse. They suffer as a result of their skin color. Albinos are known for vision problems (photophobia) and their susceptibility to skin cancer as a result of scorching sun. They burn easily hence they must constantly take care of their skin and avoid burning. Despite the numerous effects of stigmatization on psychological and social lives of people living with albinism, it is saddening to say that little is being said on how stigmatization influences their health. It is against this background that this study seeks to fill-in the gap and to find out how stigmatization influences both psychosocial and health well-being of people living with albinism.

METHODOLOGY

Research design

Descriptive research design was adopted for the study. The study sought to survey the influence of stigmatization on the psychological and health well-being of people living with albinism.

Study population

The population of the study was members of the albino foundation, a non-governmental organization committed to addressing the plight of PLWA who were of different ages, groups and sex.

Sample method

The purposive sampling method was used to select respondents from the albino foundation in Lagos state. A total of 73 respondents completed the questionnaire.

Data collection instrument

A close-ended likert type questionnaire tagged (ESPHWPLWA) was used for the study. The instrument was in two sections, A and B. Section A reflected the demographic characteristics while section B elicited statements on influence of stigmatization on both psychosocial and health well-being of PLWA. It was designed on four rating scale of strongly agreed (SA); Agreed (A); Disagreed (D); and Strongly disagreed (SD) format. The instrument was duly validated with the help of experts in the field of health social work while the reliability was ensured through the use of Cronbachs' alpha which yielded reliability coefficient $r = 0.86$; $r = 0.78$ and $r = 0.84$ respectively.

Data collection

The modified instrument was administered with the help of 2 trained research assistants. 75 questionnaires were administered but 73 was duly completed and was coded for analysis.

Data Analysis

This was done using descriptive and inferential statistics of frequency count and percentages for the demographic characteristics while section B was analyzed using Pearson Product Moment Correlation. Hypotheses were tested at 0.05 level of significance.

RESULTS

Demographic Characteristics

The result revealed that, 16 (22.0%) respondents were between 10 – 14 years old; 15 (20.5%) were between 15 – 24 years; 30 (41.1%) were between 25 – 40 years while 12 (16.4%) were above 40 years. 36 (46.6%) of the respondents were females while 39 (53.3%) were males. Also, 11 (15.1%) of the respondents were married; 58 (79.4%) were single while 4 (5.5%) were widowed. 48 (65.8%) were Christians; 22 (30.1%) were Muslims while only 3 (4.1%) were traditional worshipers. Educationally, 19 (26.2%) had B.Sc. and HND certificates, 9 (12.3%) had NCE and OND respectively. 15 (20.5%) had SSCE; 25 (34.2%) had primary school certificate while 5 (6.8%) had no formal education.

Ho1: *There is no significant correlation between stigmatization and psychological wellbeing of people living with albinism.*

Table1: *Pearson Product Moment Correlation table showing the relationship between stigmatization and psychological well-being of albinos*

Variables	Mean	St Dev.	N	R	P	Remark
Stigmatization	17.3699	9.43473	73	0.000	1.000	Sig.
Psychological well-being	24.8082	14.27669				

***correlation is significant at p-value (1.000, < 0.05)*

Table 1: shows that there is a significant correlation between stigmatization and psychological wellbeing of albinos (N = 73, $r = 0.00$, p-value (1.00, > 0.05). Therefore, the null hypothesis is rejected. This implies that stigmatization has great effect on psychological wellbeing of albinos.

Ho2: *There is no significant correlation between stigmatization and social wellbeing of people living with albinism.*

Table 2: *Pearson Product Moment Correlation table showing the relationship between stigmatization and social wellbeing of Albinos*

Variables	Mean	St Dev.	N	R	P	Remark
Stigmatization	17.3699	9.43473	73	0.857	0.021	Not Sig.
Social well-being	14.7945	15.08491				

***correlation is not significant at p-value (0.021, < 0.05)*

Table 2 shows that stigmatization does not influence the level of social wellbeing of albinos (N = 73, r = 0.86, p-value (0.02) < 0.05). Therefore, the null hypothesis is accepted. It is concluded that stigmatization does not have any effect whatsoever on the social well-being level of Albinos.

Ho3: *There is no significant correlation between stigmatization and health of people living with albinism.*

Table 3: *Pearson Product Moment Correlation table showing the relationship between stigmatisation and health of Albinos*

Variables	Mean	St Dev.	N	R	P	Remark
Stigmatization	17.3699	9.43473	73	0.789	-0.032	Not Sig.
Health well-being	21.2603	12.45774				

***correlation is not significant at p-value (-0.032, < 0.05).*

Table 3 shows that there is no significant correlation between stigmatization and health of albinos (N = 73, r = 0.79, p-value (-0.03) < 0.05). Therefore, the null hypothesis is accepted. It is concluded that stigmatisation has no effect on the health of Albinos.

DISCUSSION OF FINDINGS

The result of the study revealed that stigmatization greatly influences the psychological wellbeing of people living with albinism in Africa. This result is in line with Steine (2006) who found that Malawian albinos are considered to be disabled. Perhaps this result is a confirmation that since the year 2005 till date people still stigmatise albinos in several countries in the African continent. The result also fall in line with Geugher, Lund and Makuya (2002) who concludes that physical environment prevents rather than support children with albinism from reaching their potentials. This is not unconnected with the people's myth and superstitious believes leading to stigmatization. This, of course hinders albinos from performing fully well psychologically. It is imperative therefore, to note that nothing has actually changed from "the then" and "the now" in terms of psychological stress the African people subject the albinos to. Further, the result is in line with Estrada-Hernandez and Haper (2007) whose findings revealed that most individuals with albinism have average cognitive abilities and achievement skills secondary to stigmatization which greatly influence their psychological wellbeing. In fact, many of these individuals, struggle with the social impact of visible differences associated with albinism condition.

The result also established that there is no significant relationship between stigmatization and social life of the albinos. This, of course is also surprising. It is contrary to the findings of Estrada et al (2007) who earlier concluded that people with albinism were reported to experience many physical, mental, emotional and social challenges. In the same vein and by experience of life, a highly placed individual with albinism found it difficult to appear in public and also to associate with people because of his peculiar nature. He suffered till a very ripe age before he could get a woman of the same social ostracize who after series of mountain prayers agreed to marry the man with albinism. Howbeit, the albinos seem to be more emotionally unstable and withdrawn from the society as a result of a very obvious difference in their skin colour and those around them. This result also negates the WHO (2006) report that, individuals living with albinism tended to be more withdrawn from social situations to avoid being noticed. The report further said albinos are more emotionally unstable and had less personality than people without albinism. It is also important to note that numerous changes and development in the life of PLWA have made them to come out of their shells, and to mix with the society irrespective of the obvious differences in skin colour.

Perhaps the efforts of the health social workers and the non-governmental organizations have yielded dividend. Educating the albinos through various means on the need to keep their heads high irrespective of whatever comes their way is of paramount importance.

The health of all human beings is equally important to his or her existence. The albinos are said to have difficulty in seeing clearly. This predisposes them to fall and accidents. In the same vein, walking under the sun predisposes them to sun-burn and consequent skin cancer some people also said, albinos have body odor due to incessant perspiration as a result of hypopigmentation and their fragile skin texture. Little is also known about their reproductive life style. It could be concluded that little effort has been concerted in research on the health indices of the albinos. Esther, Hajo and Michael (2006) postulated that health care systems appear to lack responsiveness to the needs of people with albinism in most African countries. Although efforts has been focused on Albinism in Africa as a public health issue and focus has also been on health services and social issues facing the albinos, there seems to be the urgent need for adequate health statistics of the people with albinism in Africa. WHO (2006) also observed that, in addition to their health concerns, people with albinism must also deal with psychological and social challenges. Albino association, Malawi (2006) found out that, cancer victims among the albinos are as a result of lack of special mobile cancer service and that majority of them find themselves in the problem at the last minutes because of late detection and ignorance of its symptoms and signs. Central hospitals where adequate treatment could be given are not accessible to the albinos. In the same vein the health care system has not really mainstreamed issues of albinism to support the disablement and reduce the vulnerability of this group of people. Also, lack of appropriate health information on albinism, negative attitudes of some health personnel widens the gap of stigma and discrimination. People with albinism do not enjoy equal opportunities and rights to the free primary health care like any other individual. To crown it all, the health care system in most parts of Africa has no deliberate strategy to provide sun lotion and free skin therapy which are crucial health services to a better living condition of the people living with albinism. It is important to say that, somebody somewhere should rise up to the task of provision of adequate health care services for the people living with albinism specifically in Africa and across the globe.

CONCLUSIONS

Albinos are special people in Africa. They are special because of their colour and peculiarity. It is noteworthy to say that albinos in Africa are always being stigmatized even till date. The most established dreadful issue about people living with albinism is that every anatomical part of these special Specie could be used for rituals in Africa. Perhaps, this is responsible for the ritualistic killings in Tanzania in recent times. This study also established that, although there is a significant influence of stigmatization on psychological wellbeing of people living with albinism, stigmatization has no significant influence on the social and health wellbeing of albinos. Although in some quarters, stigmatization of people living with albinism is still on the increase in the African society, it could be concluded that some people living with albinism have been able to overcome stigma and develop a high sense of self-esteem. Some could socialize very well and are able to take care of their health challenges. People living with albinism should stand tall, come out of the concerns the society has put them. They must compete for quality education to be able to show to the whole world that they can do well among their counterparts. The public must also be sensitized on what albinism is and how to live in harmony with people living with albinism. Stigmatization in all aspects of human endeavor is a catalyst to self-esteem, social, psychological and health development in Africa. It must be avoided in all ramifications to ensure peaceful co-existence among the general populace.

RECOMMENDATIONS

1. Government, philanthropists and non-governmental organizations should jointly help in the provision of special clinics for the people living with albinism.
2. Albinos should be helped to develop self-esteem to overcome being stigmatized. They should be encouraged that they are natural human beings, free from unnecessary embarrassment from the general public.
3. The general public should be sensitized on the fate of people living with albinism that they are natural human beings. They are not to be used for rituals. It is barbaric and must stop.
4. The social workers should create awareness on the education of the general public on the importance of peaceful coexistence between the Albinos and the normal citizens.
5. Health social workers and allied health professionals must develop effective intervention programme to assist people living with albinism to develop self-esteem that will help them to overcome stigmatization.

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