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## **The Misconception of Albinism (Causes and Curses): Implication on Women with Albinism Invisibility in Public Health Care Centres in Nigeria**

### **Abstract**

The plight of persons with albinism (PWA) in Nigeria have long been viewed and overemphasised in general terms often explained alongside the numerous curses and stereotypes embedded in the meanings associated with the causes of albinism. This article examines the misconception and misrepresentation of facts about the causes and curses inherent in the social cultural narratives about albinos and albinism and the corollary effect on the invisibility of women with albinism (WWA) in public health care centres in Nigeria. Specifically the study investigates the nuances endangering WWA from accessing modern health care services, the socio-cultural influences, such as beliefs and traditions and the impact on behavioural outcomes of both WWA and medical practitioners. Using in-depth interviews and focus group discussions among a cross section of 52 households with WWA and 23 medical practitioners in selected public healthcare facilities across Nigeria, the study revealed that both medical practitioners and WWA are very much influenced and affected by the socio-cultural dictates of their environment which to a large extent associate PWA as 'spirit beings', 'disables' and 'harbingers of evils and death'. This has a strong relationship with the perceptions and cultural stereotypes about PWA as materials for spiritual sacrifices and rituals. Thus social exclusion is evident in the limited opportunities and behavioural outcomes in showcasing their presence in public healthcare facilities. The study therefore calls for proper engagement of the civil society towards continuous reorientation and deconstruction of the traditionally held beliefs about the causes and unfounded curses attached to albinism in Nigeria. This will no doubt encourage WWA and PWA generally to be seen accessing public and modern healthcare facilities in the 21<sup>st</sup> century Nigeria.

**Keywords:** misrepresentation, stereotypes, beliefs, invisibility, behavioural outcomes.

### **Introduction**

In this article, the inherent cultural beliefs, stereotypes formation and discrimination against persons with albinism (PWA) were examined, with particular emphasis on the implication it has on PWA access to modern healthcare services in South-west Nigeria. Albinism is a genetic condition in which a person lacks the gene for producing melanin – the pigment that protects the skin from ultraviolet light from the sun (Brilliant 2009; Thuku 2011). Persons with albinism (PWA) may lack pigmentation

in the skin, eyes and hair. The exact prevalence of albinism in the human race is not clear but estimates say that the ratio is about 1 in 17,000 (Thuku 2011; Wiete 2011). It is however, more prevalent in some parts of the world than in others. In Nigeria, there are about 6 million PWA; the prevalence is put at 1:1100 (Nigeria Demographic and Health Survey 2013). Statistically, Africa seems to have a high prevalence of PWA, of which Tanzania, Nigeria, and South Africa are worst affected (Baker et. al. 2010; Burke, 2012; Nigeria Demographic and Health Survey 2013; Thuku 2011; Wiete 2011). That said, it is important to understand that albinism is found in all races and not just among the people of the black race. There are several classes, types and sub-types of albinism defined by the measure to which there is a lack of melanin and the body part affected (National Organization for Albinism and Hypopigmentation NOAH; 2008). In most communities across the world, albinism is hardly (or not) understood. Myths and misconceptions surround the condition. However this is amplified in many parts of sub-Saharan Africa largely because the light skin tone of PWA stands out sharply in communities whose members are predominantly dark skinned. In some parts of sub-Saharan Africa, especially in Nigeria and Tanzania, the condition is traditionally thought of as evil, a curse, or as some form of punishment from the gods or the ancestors for something wrong done by the parents. In some communities, it is often thought of as nemesis emanating from the wrongdoings of an albino's mother (Ayantayo 1999). For centuries, children born with albinism have been routinely killed immediately after birth by parents and mid-wives (Abogunrin 1989; Ayantayo 1999; Delaney 2008). Myths about albinism continue to persist in many parts of Africa

The belief in witchcraft in a number of developing countries continually heightens the widespread violations of albino's rights on a daily basis (Offiong 2010; Baker et al. 2010; UNHCR 2008; Ikuomola 2015). Stepping Stones research (2005) on accusation of albinos as witches identified the Nigerian film industry (popularly referred to as Nollywood), as promoting violence against PWA via some of its movies. The film "End of the Wicked" is an example of this, since it portrays the main character (acted by an albino) as a witch (The First Post 2009). Similarly, such films regularly promote superstitious beliefs such as that of witchcraft and highlight the spread of the idea that albino's body parts may have mystical powers. Many children, youth and adults with albinism in Nigeria have been found dead, missing and sacrificed due to the belief that certain body parts can be used in rituals, to gain power, money, and success; and for the cure of impotency (Katy 2006; Stepping Stones Nigeria 2007; Ikuomola; 2015). Looking at the problems, faced by PWA, first as children and later in their adult lives, sociologically there is no doubt that surviving albinos will be faced with a myriad of challenges in their relationships with others in the larger society. A number of social vacuums such as extreme poverty, lack of access to basic resources, services and violent abuses of basic human rights provide a fertile breeding ground for distress in exploring and exploiting their agencies (Ikuomola, 2015). Health wise, the effectiveness of a country's healthcare delivery

system is often questioned and rated in terms of its inclusiveness and how best the poor and the marginalised are placed in terms of their welfare (Onwujekwe et. al., 2007). Studies on albinos have often neglected the role socio-cultural factors play on albino's access to modern healthcare services and general wellbeing. Specifically the study investigates the nuances endangering PWA from accessing modern healthcare services, the socio-cultural influences such as beliefs and traditions and the impact on behavioural outcomes of both PWA and medical practitioners. Using the health belief model as a framework in explaining behavioural outcomes and the effect of belief systems on access to healthcare, the following research questions guided the study: what are the factors affecting PWA access to modern healthcare services, and the cultural barriers facing PWA in their healthcare decision making?

## **Methodology**

The study employed the grounded theory approach where research questions emerged from interviews. Identified PWA were simply asked to narrate the cultural beliefs surrounding albinism and its impact in accessing modern healthcare services. This was done using Wengraf's (2001), life -history qualitative research interviewing, which involves a narrative and semi-structured method questionnaire "tell me the story/history of your life". This approach is used in order to give voice to people who are usually not heard which buttressed much about the identity, or self— as it does about the events, structural conditions and daily life experiences of PWA. This was used in line with the Health Belief Model (HBM) in understanding PWA health seeking behaviour. This model is used normally to investigate health related behavior, such as accessibility and patronage of modern healthcare facilities and medication (Burak and Meyer, 1997). The HBM was originally designed to address issues for people who do not participate in prevention programmes (Bloom and Gundlach, 2000). The study was conducted among a cross section of 52 households with women with albinism (WWA) and 23 medical practitioners in selected public healthcare facilities across Nigeria between April 2017 and February 2018. The interviews were conducted in Yoruba language with the interjection of pidgin and standard English. It lasted between 50 minutes and one hour 30 minutes, per individual. The data generated was analysed qualitatively, using ethnography summaries of verbatim quotations.

## **Empirical findings and discussion**

There were several issues raised by participants buttressing the ways and manners, the socio-cultural beliefs and practices among the Yoruba, stigmatise and undermine PWA access to modern and public healthcare services. For the sake of brevity, the analysis of the data was discussed under the major subthemes of: socio-cultural conception of albinism and albinos identity in South-west Nigeria; Implication of

socialization and social exclusion in accessing modern healthcare services; medical practitioners' narratives of PWA access to healthcare services and PWA avoidance and apathy towards modern healthcare facilities and services.

### **Socio-cultural conception of albinism and albinos identity in South-west Nigeria**

The relationship between one's identity and tradition is very much intimate in understanding social realities pertaining to healthcare access in different communities. People understand and construct their identities in terms of the traditions that are a part of them and, as Fay (1987) illuminates, "coming to be a person is in fact appropriating certain material of one's cultural tradition, and continuing to be a person's means of working through, developing, and extending this material; and this always involves operating in terms of tradition" (Fay, 1987:160). An appreciation of the importance of tradition in shaping identity enhances our understanding of how tradition imposes limits on the change that is possible in a society. No matter how revolutionary the change, some continuity will remain in the form of certain modes of thoughts, perceptions and relationships. Thus certain habitual ways of behaviour will surface and survive as important ingredients in the identities of a people "who are what they are because they so deeply share them". The oldest of the respondents narrated the traditional and cultural beliefs about albinos as thus:

In Yoruba myths, folktales and legends, albinos are classified as people with disability and spirit beings popularly referred to as "*Eni Orisa*" (Divine beings or people of the gods). It is believed that they are the closest allies of *Obatala*, the Yoruba god of creation (R12/Male/65 years/Osun State).

This belief according to historical literature cuts across West and Central Africa, down to the Caribbean, Central and South Americas. According to (Ford, 2000), he noted that the Yoruba cultural beliefs continue to have a deep influence in countries like Brazil, Haiti and Cuba, where *Obatala* is the god of creation and life. The Yoruba story about creation of human beings explains that "*Obatala* tired of just his cat as a companion, and one day determined that he should make men and women to share the earth with him. Working non-stop, he dug up bits of clay, which he fashioned into small figures, men and women, shaped like himself. Eventually, *Obatala* grew exhausted and thirsty from all this work and longed for some palm wine to refresh and rejuvenate himself, he became drunk, weak and destabilised, after which inferior beings were created (Ford 2000:151). This was also narrated by Ijimere Obotunde, a Yoruba playwright in his play "The imprisonment of *Obatala*":

You drank the milky wine of the palm  
Cool and sizzling it was in the morning,  
Fermenting in the Calabash  
Its sweet foam overflowed

Like the eyes of a woman in love  
 You refreshed yourself in the morning  
 But by evening time your hands were unsteady,  
 Your senses dull, your fingertips numbed (Ljimere, cited in Ford 2000: 153–154).

Thus it was a drunk *Obatala*, who was unable to model the clay properly, which resulted in the creation of disabled persons: his fingers had become unsteady. And some of the figures he next created reflected his impaired condition: they were albinos, cripples, hunchbacks, dwarfs or deaf mutes (Abogunrin 1989; Ayantayo, 1999; Ford 2000). But in his drunken state *Obatala* failed to notice these deformities. When the haze of the palm wine wore off, *Obatala* looked around and, seeing all the malformed beings, realized what misery his drunkenness had wrought. His heart was filled with compassion and remorse. “Never,” he said to himself, “never again will I drink palm wine. And I shall always be the protector of those who have been created with deformities and imperfections.” (Ford 2000:151).

Wole Soyinka, Nobel laureate and a Yoruba playwright, says that this story brings the god firmly within the human attribute of fallibility. “Since human fallibility is known to entail certain disharmonious consequences for society, it also requires a search for remedial activities, and it is this cycle which ensures the constant regenerative process of the universe. By bringing the gods within this cycle, a continuity of cosmic regulation involving the worlds of the ancestor and the unborn is also guaranteed (Ford 2000). It was observed through interactions with both medical practitioners and PWA, that persons with albinism were discriminated against due to some beliefs. The common beliefs are:

‘They are cursed and are misfits in the society’ (R15/Male/29 years/Oyo State)

‘An albino child is a reincarnation, a cursed child, but a special child from the ‘gods’ for a special purpose’ (R67/Female/31 years/Lagos State).

Respondents believed some of these misconceptions are life threatening and place children with albinism in a state of vulnerability since man is generally ruled by belief systems. There are cases of suspected albino witches being abandoned by their parents and guardians, taken to the forest and slaughtered, bathed in acid, burned alive, poisoned to death with local poison berry in Nigeria and other countries in Africa (Offiong 2010; Baker et al. 2010 and Ikuomola 2015). Similar violence, associated with creation myths abound also among the indigenous Amerindian tribes in the Americas, some of which include references to the disabled persons (Baker et al., 2010; Erodes & Ortiz. 1984). For example, Yuma Amerindian tribe has a creation myth very similar to the Yoruba myth. For the Yuma, the world was created by a pair of twin brothers, Kokomaht, the All-father, who is good and his blind brother the subterranean Bakothal, who personifies evil. Both brothers take birth out of the depths of a lake. Kokomaht, the “good” elder brother, tricks his younger

twin to open his eyes under the water and thus, be born blind, since Kokomaht already knew that his younger brother was going to be evil. The two brothers created the human beings:

Bakothal went on trying to make humans, piecing together seven beings out of earth. All were imperfect.

“What are you making?” Kokomaht asked. “People” answered Bakothal. “Here,” said Kokomaht, “feel these people I’ve made. Yours have no hands or feet.

Here; feel; mine have fingers, thumbs, to work, to fashion things, to draw bows, to pick fruit” (Erodes & Ortiz, 1984:76).

The above examples from different cultures present certain common features related to their views about disability like charity, need for care, imperfection and divine punishment. A common tradition among many different cultures is the belief related to impairments of albinos, often seen as sign of special skills or powers. Cahill (1998) noted among people as widely dispersed as the African Bushmen, the Samoyed, and the Chinese, a similar belief in a series of lunar creatures with missing hand or foot (like the incomplete moon) and other forms of human disabilities characterized by their power to bring rain and subsequent fertility.

### **Socialisation and social exclusion: Implication on PWA access to modern healthcare services**

The linkage between societal discrimination and the socialisation processes arises from the fact that culture through socialisation defines who we are, and how we cater for ourselves and others, be it male or female, as evident in various societal institutions of which the healthcare system is very important in different social and cultural contexts. Parker et al. (2000) noted that discrimination and what to discriminate against is cultivated first through socialisation as described by in the analysis of social identity as cited in Parker (2009):

All biological males and females must undergo a process of socialisation in which culturally specific notions of masculinity and femininity are shaped across the life course. It is through this process of socialisation that individuals learn the desires, feelings, roles and practices typical of their cohorts or statuses within society – as well as the alternatives that their culture opens up to them (P. 257).

The lack of knowledge, misinformation and negative attitudes about albinism often buildup to the exclusionary tendencies manifested by ‘others’ in the same society towards PWA and PWA themselves. As reported, PWA (over 25 percent) interviewed in the rural areas of Osun, Ogun, Ondo, Oyo and Ekiti noted several times their parents would hide them from the public. In the words of one of the respondents (R21), she disclosed that it was as a result of the fear of being kidnapped and

the associated stigma attached to albino children as 'not children' that prompted many parents to have behaved that way. Another (R14), reiterated that it was because their parents believed that they could do nothing to help the children, still R72 noted that it was because they felt ashamed by them.

Starting from early childhood to adulthood at one point in time or the other, PWA seems to have been discriminated against. This was evident in their experiences in both private and public hospitals. The differential treatment at home and associations outside the home have a lot of roles to play in the way PWA self-esteem are built. This explains some of the reasons why many PWA are more likely than others to develop low self-esteem in seeking modern healthcare services, and some negative attitudes about themselves and their abilities. An excerpt from three life history interviews showed clearly that there are exclusionary tendencies which limit the avenues for PWA in seeking modern healthcare services. A female head teacher noted:

Though many doctors accept PWA as they are superficially, but a long interaction with them in the hospital will bring out the true colour of these doctors out. I once had a terrible experience with a male doctor in Lagos Island general hospital, then as a young girl I was always having severe menstrual pain, every month, one morning I decided to visit the hospital after a long while. I was tired waiting until it got to my turn, I narrated my condition and wanted a remedy that will stop the pain once and for all, so I patiently narrated my plight to the doctor. I observed that he was not paying attention to me and probably he was in a hurry to prescribe pain killers for me. So I stood up and told my parents that I will never go to a public hospital in my life (R15/Female/37 years/Ekiti State).

This account shows that many PWA will prefer normal and extra-attention being given to them just like others. Similarly like most minorities, they expect that they should be treated with respect as humans, and should be given preferential treatment wherever they find themselves. A respondent recalled her experience in one of the public hospitals in Osun:

There are incidents too numerous to mention. I can still remember, I stretched my hands to shake somebody in the hospital's waiting room, and I was told 'don't touch me'. Even when people come in to have their seat close to you; they just suddenly leave you, sometimes they leave a whole row of seat for you and prefer standing, till it gets to their turn to see the doctor (R47/Female/29 years/Osun State).

Another echoed:

If public hospitals are the last option in Nigeria, I will rather die. But thank God the private ones are there, though very expensive but affordable. Also, traditional healers are becoming modern. My experience sometime in 2010 is still very fresh in my memory. As a young man I was having a severe typhoid and persistent sight problems and was admitted into the state General hospital, Ondo, in a twelve man-room, only for the nurse to ask the patient by my bedside if he would prefer another section of the room or a differ-

ent room entirely. Prior to these questions I already observed the partiality in treatment, so I told the nurse, that she is discriminating just like others in the society. In response she said she does not see the discriminations I speak about in society. So I looked her deep in her eyes and asked her if she would marry an Albino? She lost her breath. After a while she eventually answered in the affirmative. I said to her 'I do not need to be a psychologist' to know that, that is a secondary opinion' (R38/Female/37 years/Ondo State).

Similarly, R21, noted that she has come to rely more on trado-medical care and home-service anytime she is down health wise. For R45, she would deliberately visit the hospital at night when the population of patients and their relatives must have reduced in numbers:

Like the proverbial Nicodemus, clandestine and late night visitation and patronage of public hospitals have become a way out for me anytime I feel like seeing my doctor or pharmacist (R45/Female/36 years/Ogun State).

PWA responses revealed the extent to which human experiences are shaped, transformed, and understood through beliefs, expectations (real or imagined), behaviours (overt and covert) and linguistic representation. The vague and subjective sensations that characterise cognitively unstructured life experiences take on meaning and order when it is articulated in communication. Putting experience into words, whether we do this verbally, in writing, or in thought, transforms the actual experience into a communicable representation of it (Sandelowski, 1994). Thus, speech forms are not the experiences themselves, but a socially and culturally constructed device for creating shared understandings about them.

### **Narratives of Medical Practitioners towards PWA access to healthcare services**

Accounts of medical personnel tend to differ from PWA, but they were all in agreement that only few PWA (most especially women with albinism) patronise their services because of the cultural and superstitious beliefs about albinos and their nature in society. This further opens up the space to which disparities are observed in modern healthcare services despite the challenges of inaccessible physical environments, social assumptions and prejudices, and other inflexible policies and procedures posed by society on persons with disability (Disability Rights & Education Defense Fund, 2011). Instances where other patients have abused and misused their rights against PWA in hospitals were revealed. The right to request for a different bed-space when an albino is admitted into the same ward or room was noted as painful whenever such request are made, nevertheless patients right must be respected. An albino doctor (R55) noted that the stigmatisation of PWA cuts across all facets of the society and not necessarily as a patient:

It is the same way PWA are stigmatised in most places irrespective of one's education and status. As a medical doctor when I am on duties, even some ignorant patients will



deliberately avoid their turn in order to make way for others who won't mind receiving diagnosis and prescriptions from me. It is a funny and difficult world for one to be an albino in this part of the world (R55/ Male/34 years/Ogun State).

In support of the above, a female midwife explained how pregnant women avoid her services during antenatal routines:

Even women and mothers to be, will gossip and show attitudes whenever I am on duty to attend to them. Right here in the hospital wards, often you will hear: 'What can this albino nurse do? Can she see or feel my condition? Has she got any experience about child bearing? She does not see well and moreover she is not a mother and may not know how it feels to be one. Comments like these are directed towards PWA and more for women with albinism everywhere (R69/Female/42 years/Lagos State).

Another medical practitioner with albinism (R49) buttressed the fact that as a trained doctor she is admired as a doctor from afar but not at a close range when attending to patients who are non-albino; this is even more obvious when dealing with patients who not educated:

Some patients look at me as some extraordinary person who has found a job in the wrong profession and not as human like any other doctor or health professionals. It is only with well educated patients that I find joy in this job. Most will not discriminate and will accept my services wholeheartedly. In my seven years as a medical doctor, there was a particular case of a patient among many whom I attended to, only for him to seek for reassignment to another doctor just because he did not have confidence in my skin. Unfortunately for him he was told that I am the only specialist in ENT (ear, nose and throat) diseases. And I think he later discontinued his medical follow up. There are so many other minor attitudinal issues surrounding us as PWA. I have come to take it as fun, as it makes my job sometimes less stressful because directly and indirectly, excess workloads are transferred to other doctors on duty (R49/Female/38 years/Ogun State).

The patronage and frequencies of PWA/WWA visiting a hospital was a major factor driving this research, it was therefore necessary to ask the question 'how regularly do you treat or attend to PWA', the responses were: 'I cannot remember' (18 out of the 23 medical staff), 'I do not take records' (15 of the 23 medical staff), 'only few of them' (8 out of the 23 medical staff). In one of the interviews with R11, the Chief Medical Director of a general hospital in Akoko, Ondo state, he was of the opinion that younger medical doctors and nurses were often perplexed when PWA are on admission, for the simple reason that they may not have seen or been in contact with one in their lifetime as a medical personnel. He described first time experiences of younger medical staff as an issue that PWA, especially adults may take seriously:

For the fact that there are very few PWA in every part of the country or even in the communities where state owned clinics and hospitals are present, younger doctors, nurses and midwives may not have had any opportunity attending to PWA as a trainee. Thus

first contact may create an unpleasant scenario between them and not necessarily to avoid them when they are admitted (R11/Male/49 years/Ondo State).

R17, a female nurse in the same hospital noted that it is not only medical practitioners that are affected with the cultural beliefs about albinos but that PWA also have their preconditioned and biased cultural expectations about doctors and nurses. Thus medical practitioners' general reservations and calmness towards PWA were narrated as often misinterpreted as stigma:

PWA often tends to see us as people on one side and them on the other. This goes a long way in explaining why some of them feel easily threatened, offended and reserved in interacting freely with us. So when I try to be friendly it looks as if I am trying to adjust my behaviour and when am not, it looks like I am stigmatising them. So many of us are extremely careful about the way we handle people with one form of ability or disability in other not to be queried. In all we are all human! (R17/Female/41 years/Ondo State)

A doctor in Oyo noted that sometimes other patients may determine the way and manner responses are conditioned towards others:

If a patient feel that they are not comfortable with an albino in the same corner or room, depending on the status of the person, it is just necessary for us to use our discretions, which may also be misinterpreted. So there is always room for misinterpretations of medical practitioners' actions and inactions in some encounters with PWA in society (R70/Male/53 years/Oyo State).

When probed about possible interventions by the government and other organisations, most of the medical staff claimed they were not aware of any action by the government, but very few were aware of civil societies and international organisations like the World Health Organisation (WHO), United Nation Children Education Fund (UNICEF), and The Albino Foundation (TAF), among others mentioned as constantly championing the cause of albinos and other disadvantaged minorities. It is therefore obvious that governments at various levels and at larger society are yet to accord albinism its due recognition and therefore fail to legislate adequately on their rights, protection and general welfare (UNICEF 2011). It is in this regard that advocacy group such as The Albino foundation (TAF) in Nigeria has continuously agitate for a national official framework in place to provide welfare education and health support to PWA as many parents are forced and solely responsible for the care and support of their children (UNICEF 2011; Ikuomola 2015).

### **Avoidance and apathy towards modern health facilities: Implications on self medication**

The UNICEF 2011 survey report affirmed that name calling, taunting and shunning are the major forms of discrimination experienced by persons with albinism wherever they are found. And this was also noted as widespread in a number of public

healthcare facilities Nigeria irrespective of gender or age of PWA. Other studies showed that the albinism as a condition (biologically and socially) makes PWA easy target for bullying, physical molestation and false accusation with resultant effect on their visibility in public healthcare facilities (Ikuomola 2015; UNICEF 2011; Wiete 2011).

A female businesswoman with albinism (R4) noted:

One of the reasons you won't find me in a public hospital is the crowd, especially of children singing local song such as '*oyinbo pepper, eat eat pepper you go yellow well well, you go yellow more more...*' this literally means that an albino is a foreigner (Whiteman) that looks like pepper, and s/he must not eat pepper, if s/he does s/he becomes intensively yellow" apart from this song being sung by children in public hospitals, their wards and parents also join in admiring their children instead of correcting them. Other times, fellow patients stylishly avoid us, they see us as smelling as it is believed that albinos have odours and other derogatory remarks (R4/Female/56 years/Lagos State).

Another remarked:

They see us as cursed, as spirit beings that should not been seen during the day. The belief is that night time is the ideal time for us to come to the hospital. Its that bad! (R15/Female/28 years/Oyo State)

Remarks such as this, directly or indirectly have led many WWA to withdraw from public healthcare centres and cautiously seek medical care in other places where they are more likely to enjoy their privacy and be respected. One of such is to seek modern healthcare services in the hands of medical practitioners who operate their privately owned hospitals and clinics irrespective of the cost, as well as patronage of patent medicine shops as echoed by the respondent below (R29). Other timestrado-medical practitioners and spiritualists were said to be patronised.

At a tend age my parents have to make do with private medical practitioners who will visit me and other times send their nurses to see to my health whenever I am sick. So I have come to realised that it is much more better that way, than me going to the public hospitals where one is likely to come back home unhappy. It is expensive though; seeking healthcare with private practitioners, nevertheless brings an unquantifiable happiness, and as the saying goes good health cannot be traded for gold or silver (R29/Female/27 years/Ekiti State).

From the aforementioned, WWA' illness behaviour may have negative effects on successful delivery of medical services in Nigeria, especially among those in the low income bracket. The implication is that there is the likelihood of competition between modern and alternative healthcare systems. Apart from the competition, the likelihood of many PWA falling into the hands of quacks practising as medical doctors and health providers in the rural areas cannot be undermined. R11 noted that

Sometimes we are forced to patronise healthcare providers who are not 'real' medical practitioners in the villages to avoid the crowd in public hospitals in the city centres (Female/37 years/Ondo State).

Several studies attributed the continuous patronage of alternative healthcare in modern times to the relative cheaper cost assured on one hand, and the social distance modern healthcare services create through behavioural outcomes of medical and non-medical personnel in various hospitals in Africa (Onwujekwe *et al.*, 2008; 2010). The social distance emanates from the stigmatising attitude of the people, (sometimes by medical practitioners) and the hospital likened to a prison (Ojanuga & Lefcowitz 1982; Onwujekwe *et al.*, 2010) through placement of patients into different wards. Similarly, the question of cost (Onwujekwe *et al.*, 2007; 2010), willingness to pay (Onwujekwe *et al.*, 2008; 2010), ability to pay (Onwujekwe *et al.*, 2010) and mistreatment of persons with disability (UNICEF 2011), are important determinants of access to and utilisation of modern health care systems. Evidences are glaring that the mistreatment of persons with disabilities is quite common at community-level, where most of the primary health centres are located (UNICEF 2011; Young 1999).

The discourse of social exclusion in healthcare services and centres has shown that marginalisation is at its peak when people are classified as disables, underclass, and homeless, among others (Young 1999). For WWA and PWA, cultural exclusion is as a result of the perceptions and dictates, which define who they are as portrayed in the mythology of albinos as spirit beings and disables. The effect on their lifestyles is far overwhelming, as many have been socialised to trust and always seek attention of family members in whatever they are to do or must do. Thus PWA narrated, high patronage of patent medical shops popularly referred to as 'chemist' and home services by doctors and nurses, and quacks in the corridors of the healthcare services as alternatives to visiting a public hospital or health centres:

It has been long I visited a clinic or hospital because the chemist shops are very reliable and the owners are always friendly and ready to help. Moreover I can always count on them whenever I am ill, and the shops are within reasonable distance compare with state owned hospitals (R1/Female/31 years/Ogun State).

For another (R23), the crowd in most public hospital creates a barrier which tends to discourage PWA from seeking medical attention in hospitals.

I often detest going to public hospitals, because everybody there will look at you as if you are from another planet. This makes me feel sad anytime I returned home from the hospital or nearby health centres, it gives me nightmares. So I have continuously been using local herbs for the past ten years whenever I am sick (R23/Female/52 years/Oyo State).

A nursing mother (R43) in Ondo State, who happens to live very close to a general hospital, noted that:

Despite the proximity to the hospital, the distant privately owned clinic is much more preferred because of the friendly and accommodating nature of the staff to every patient without any form of discrimination (R73/Female/28 years/Ondo State).

In a similar narrative and tone, another (R44) said:

The private clinics are better equipped with less crowd, though more expensive. I prefer them to public ones because you pay for their services and humanly attention is given in return. This is quite different from the public hospitals, where one is treated as an experimental case especially for a first timer who has not been opportune to interact with a sick albino. Some time nurses first stigmatises you with horrible looks and questions such as 'are you here to see someone?' do you have a relative around? Are you sick? These are questions they won't ask others who are not albinos (R44/Female/37 years/Lagos State).

Cases of social barriers and discriminations create a definition of PWA otherness, which in turn marginalises, disempowers and excludes PWA in the broader scheme of things in accessing modern healthcare (Weis 1995). Though some scholars have argued that othering serves a psychological purpose, where an 'exclusionary urge' (Hubbard 1998:281) satisfies a need to keep psycho- and socio-spatial proximity 'clean' from threatening others, and maintaining moral normality. It is however revealing that a number of PWA narrated their ordeals in terms of avoidance, othering, and their dependence on self medication to avoid public encounters laced with stigma and fears. A specific narrative revealed thus:

I make myself alright by asking friends and chemist owners what drug I should take whenever I am not feeling well. For the past 25 years I have not fallen sick to the extent of going to the hospital, at worse I will call a nearby nurse to fix a drip on me in the comfort of my home and in the midst of my family members. Because going to the hospital one will definitely come back home with many unpalatable things about albinos, which do not heal over time (R31/Female/57 years/Osun State).

The challenges of poor attitudes shown by health workers, lack of drugs and medical aids are not unique problems to PWA and others with disabilities (Tsoka 2012). However, considering the effort parents and guardians put forward in introducing their children to health facilities, the attitude of medical practitioners and the absence of drugs in many healthcare facilities create a fertile ground for apathy, and adult WWA often resort to over-the-counter drugs, traditional herbs, and only visiting a health facility when seriously ill. Comments about self medication were predominant among PWA, thus they also contribute to the statistics of many who self medicate in the country. R31, echoed: 'I rather pay for health, not stigma'. Nothing that she prefers traditional healers because of the privacy rather than paying for services in the hospital and get a whole lot of stigma and curses in return.

## Conclusion

This study examined the misconception of albinism and the implication on women with albinism Invisibility in public healthcare centres in Nigeria. Several narratives reveal the misconceptions associated with albinism (causes and curses) associated with meanings and perceptions and the social impact on WWA. Culture tends to explain why there are such negative perceptions and misrepresentations about albinism and PWA, from various dispositions of disability and spirit beings. The tradition depicts PWA as the closest allies of local deities (god of creation). This belief system sees and informs the continuous stigmatisation of WWA and their inherent withdrawal from the public sphere, and less active in the domain of modern healthcare providers and services. It is vitally important to distinguish between disability as a natural part of the human condition, and disability-related health disparities that can lead to compromised care, institutionalization of ill health, and unwarranted death. Stigma and discrimination have strong impact on WWA, in accessing modern healthcare services. These are consequences that do not follow scientific reasons, rather, it refers to the many barriers that stand in the way of people perceived to be with disabilities as in the case of WWA.

These nuances play vital roles in explaining the invisibility of WWA accessing modern public healthcare facilities in Nigeria. Ultimately global public health goals and response to the need of communities and populations of minorities and the marginalised especially in Africa are hindered. The study concludes that WWA (and PWA in general) access to modern healthcare services is hindered by the socio-cultural conception and associated spiritual and derogatory attributes of who an albino is. Thus the study recommends a robust healthcare policy and research that will cater for the medical needs of minority groups (persons with albinism) that are socially marginalised in accessing modern and public healthcare services in Nigeria, bearing in mind the Bamako Initiative programme of 1987, which highlight the need for modern healthcare services and delivery to be accessible, affordable and available to all without categorisation as evident in the influence culture plays in the lives of PWA. Understanding these myriad barriers and disparities intermingling on PWA access to modern public healthcare services and facilities will foster an appropriate healthcare policy and education of present and future leaders who eventually will translate public health research into practice and policies to improving the health of all humans in society. When making these a reality the role of government and civil society cannot be overemphasised. In these ways, positive government action can engender civil society in regions or amongst particular groups where it has been traditionally weak, such as on issues of the invisibility of WWA and PWA in the public healthcare corridors in Nigeria.

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