

The Misconception of Albinism (Causes and Curses): Implication on Maternal Health of Women with Albinism and their Invisibility in Public Healthcare Centres in Nigeria

Extended Abstract

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 maternal health of women with albinism and their invisibility and access to modern healthcare services in South-west Nigeria. Statistically, Africa seems to have a high prevalence of PWA, of which Tanzania, Nigeria, and South Africa are worst affected (Baker et. al. 2010; Thuku 2011; UNICEF, 2011; Wiete 2011). 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 Nigeria, 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. Looking at the problems, faced by PWA, first as children and later in their adult lives, demographically and 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. Thus in a number of institutions PWA are often invisible and socio-culturally neglected. As in the case of healthcare services in several institutions, persons with disability (PWD) most especially for married and/or pregnant women with albinism, they are often not seen accessing healthcare services in Nigeria. 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, the disable and the marginalised are placed in terms of their welfare. (UNICEF, 2011). 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 women with albinism (WWA) from accessing modern healthcare services, the socio-cultural influences such as beliefs and traditions and the impact on behavioural outcomes of both WWA 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 maternal health of women with albinism and their invisibility in public healthcare centres in Nigeria as well as 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 WWA 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” in relation to access and barriers to maternal healthcare and their invisibility in public healthcare facilities. 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 behaviour, 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 74 households with WWA and 37 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 women and persons with albinism access to modern and public healthcare services in general. 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 women, mothers with albinism access to healthcare services before and during pregnancy and their 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. 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". It was also 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' 'An albino child or a child from an albino is a reincarnation, a cursed child, but a special child from the 'gods' for a special people and spiritual purpose'. Respondents believed some of these misconceptions are life threatening and place both PWA and WWA in a state of vulnerability since the Yoruba like other communities is generally ruled by belief systems. There are narratives of suspected WWA witches being abandoned by their husbands, by their parents and guardians, taken to the forest and slaughtered, bathed in acid, burned alive, poisoned to death and others frustrated and losing their pregnancy in the process.

Narratives of Medical Practitioners towards PWA access to healthcare services: Accounts of medical personnel tend to differ from WWA, 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. 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 am on duty to attend to them. Right here in the hospital wards, often you will here: '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. Similarly for the fact that there are very few WWA and 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. .A female nurse noted that it is not only medical practitioners that are affected with the cultural beliefs about albinos but that PWA also have their own 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.

Avoidance and apathy towards modern health facilities: Implications on self medication: Remarks such as name calling, bullying, physical molestation and false accusations 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 respondents). Other times trado-medical practitioners and spiritualists were said to be patronised.

Conclusion and recommendations: These nuances play vital roles in explaining the invisibility of WWA accessing modern public healthcare facilities in Nigeria and the implication on maternal health of PWA. Ultimately global public health goals and response to the need of communities and populations of minorities and the marginalised especially in Nigeria are hindered. The study concludes that WWA (and PWA in general) access to modern healthcare services are 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.

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