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Lifelong Agony Among People with Albinism (PWA): Tales From Lake Zone in Tanzania

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Abstract
A qualitative study conducted in the northern regions surrounding Lake Victoria in Tanzania, reveals that, People with Albinism (PWA) have been harshly treated for long. Mothers were required to terminate lives of their abnormally born infants (like albino infants). Besides lifelong challenges due to albinism condition, people searched for their body parts even after "being hidden" in unmarked graves after their deaths. Beliefs fuelling such ill-treatment on PWA are deep rooted and intertwined among peoples' mind under influence of cultural beliefs existing for several decades. Proper approach should be designed for permanent solution of the long existed inhumane practices against People with Albinism.

Keywords: Lifelong Agony, Alinism, PWA, Tanzania

1. Introduction

Burke *et al*., (2014) defines albinism as a group of rare inherited conditions which affects the pigments in eyes, hair and skin of people throughout the world including Africa. Albinism in Africa is accompanied with a number of myths and stereotypes regarding albinism (Phatoli *et al*., 2015). This paper presents explanations and experiences from People with Albinism (PWA). Some tales from people living with albinism in areas most hit by the inhumane practices against them are explained in this paper. Tales on inhumane practices which compelled people with albinism of all ages to demand police protection with some of such people taking refuge in places considered to be safe (Bucaro, 2010: Mushi, 2009; Natukunda and Ngatya, 2008).

Albinism like other kinds of disabilities in most part of Africa is associated with a sense of worthlessness or uselessness (Bucaro, 2010). Deal (2007) narrates that, negative beliefs and attitudes surrounding people with disabilities, make people with albinism feel devalued and insecure. Mysterious abduction and killing of persons with albinism evoke feelings of uneasiness and insecurity in their communities. In some cases attacks go unreported and undocumented due to the code of silence surrounding such crimes as well as the vulnerability of the targeted population (United Nations Human Rights Council Advisory Committee (2014) Cited by Mswela, 2017).

According to Witchcraft and Human Rights Information Network (2016), murders of People with Albinism (PWA) is part of a larger global problem where violence is perpetuated due to beliefs in witchcraft, *juju, muti* or spirit possession. It is almost always that, the most vulnerable groups are children, women, the elderly and disabled who are the most targeted. The Guardians (2019), elaborate that, myths and misperceptions surrounding albinism in Tanzania are too numerous to count. This paper presents tales from informants on beliefs and practices related to people with albinism in the study regions.

2. Methodology

This study aimed at exploring and understanding more on beliefs and practices related to people with albinism. Due to sensitivity of the study, qualitative methods were used in data collection. Interviews with key informants were conducted. This study was in search of in-depth knowledge and experiences on a sensitive issue. The methods enabled the study to learn a lot from interviewees concerning their views and knowledge on albinism.

Key informants interviews aimed at creating comfortable environment for them to talk openly and freely than if they had been in a group due to sensitivity of the issue studied. Selection of key informants for interviews depended on the quality of respondents selected. Collected data were interpreted and organized into themes considering words, meanings, and messages that were communicated.

3. Tales on Practices and Beliefs Related to PWA

From interviews conducted, below are narrated issues concerning the fate of People with Albinism.

3. Uncelebrated births of Children with Albinism

According to Van Beek (2002), birth is both a biological experience and a cultural construct. It is the event through which societies do celebrate the rebirth of their future. However, births of children with albinism were unwelcomed in most African culture (Barnes, 1985). Taylor *et al.,* 2019, elaborate that;-

> *Babies born with the inherited condition (albinism), resulting in reduced melanin pigment in their hair, skin and eyes, are vulnerable in multiple ways in Africa: as children, as visually impaired, as socially ostracised, isolated and excluded, and as potential victims of witchcraft-related violence targeted for their body parts for use in 'lucky' charms thought to bring good fortune.*

Children born with abnormality were seen as threats to the wellbeing of the respective community. It was believed that such children were evil or carriers of misfortunes. If such children were left to live, the society members expected drought or fierce stormy rain accompanied with thunderstorms until "*something urgent*" was done. A key informant insisted that:

> *"Parents of children with albinism knew what they were supposed to do immediately after birth of such child in order to save the community from angry gods. Therefore, once the child was missing in the concerned household, the whole community knew what had actually had happened…"*

According to UNICEF (2010), in many African societies, the birth of twins, as well as other births considered "abnormal" (like in case of breech birth or birth of an albinos child), were generally surrounded by complex system of representations and rituals. Unwelcomed children were thrown away from families in some areas specified for such occasions. Barnes (1985) elaborates that, this practice was common in many African societies and it is through it many unfortunate infants were killed secretly and mercilessly. While mothers often refused to breastfeed albino babies and in most cases having an albino children resulted into separation of parents and breakage of marriage (Obsevers, 2009). According to Kromberg (2018) as cited by Taylor, (2019), babies born with albinism in Africa, were faced by societies that demonized, marginalized, stigmatized and discriminated those who had albinism.

In some areas mothers were required to bury their newborns alive in secret places. A key informant elaborated that:

> *"Mothers who gave birth to children who were not wanted in the community took their children secretly early in the morning to bury them alive where they thought it was convenient…"*

Parents who could not bury their babies alive, poisoned them and left them to die silently on their beds. It was narrated that;-

> *"In our areas "Ugolo" (snuff tobacco) was a common poison which was commonly available and used to kill newborns thought to be unfit to remain alive for the wellbeing of the community".*

According to Taylor *et al*., (2019), in the case of children (children with albinism), their murders often took place shortly after birth or at the hands of family members. Lives of PWA were snuffed out of them quietly, and the community went on with their businesses as if nothing has happened. Albino babies were not allowed to survive the next day after birth (Bello, 2017). Debrah (2017) further elaborates that, twins and albinos were seen as bad luck within these communities and they were not allowed to live.

3.2 Denied to access education

According to Mesaki (2008), majority of albinos are semi-literate many of them do not reach beyond primary school education. Makulilo (2010) narrates that, PWA do not have equal access to education and when they get an educational opportunity, it is very difficult for them to attend because of low security. In fact, most African Governments has not taken proper measures to provide education for those children (Nzagi, 2009). Franklin *et al.,* (2018), narrate that, parents fear sending their children to school due to fear for their safety while walking to school and lack confidence in teachers' abilities to keep them safe. According to Human Rights Watch (2019), Children with albinism face numerous obstacles at school, including bullying by students and sometimes teachers, little to no reasonable accommodation for their low vision, and requirements to participate in physical education classes outside without proper protection from the sun.

Unstable PWA's families were reported as another challenge for attainment of education among children with albinism. A Key respondent told how she could not go beyond standard three in her primary education due to family disputes, which rose after her birth as a fifth child with albinism in her family. She further narrated:-

> *"Upon separation of my parents, I could no longer live with any of my parents who actually did not need to see a child with albinism in the family. As a result I could not go on schooling".*

Schools in most cases put students with albinism under the same conditions as other students without taking into account the visual impairment associated with albinism (Thuku, 2011). Poor vision among students with albinism may cause students with albinism to be slow learners either due to the inability to see the black board clearly or the inability to read books and other learning materials. Such unfriendly environment may have contributed to poor academic performances and low education levels for persons with albinism. Most parents seem to be unable and sometimes unwilling to send their children to high levels of education, thus primary level of education is the highest level the majority can reach because it is compulsory and provided free in public schools. According to Chege (Undated) many people mistakenly think that albinos are mentally retarded and discourage their parents from taking them to school thinking that it is wastage of money. In most cases their presence is still felt by societies to be a financial burden (Alghazo, 2002).

3.3 Denied Parental Care

Studies suggest that, most of African children with albinism are raised by single mothers, with subsequent financial difficulties impacting on education and health (Bucaro, 2010, Cited by Taylor, 2019). According to Chege (2012), almost 90% of albinos living in most African regions are raised by single mothers, because the fathers believe their wives had affairs out of the marriages which lead to having children with albinism. According to Baker *et al.,* (2010), the web of beliefs associated with albinism has a profound influence on the lives of people with this condition, from the moment of their birth until their death, interfering with access to education, employment and marriage.

In the study regions, children had been attacked most, while women were attacked in few cases as opposed to adult men with albinism who were rarely attacked. A key informant explained that:-

> *"Children with albinism are attacked most. May be, it is because it is easier to get them, it requires less effort compared to adults".*

In the late 2000s, the Government of Tanzania set forth measures designed to ensure the physical safety of children with albinism, such measures included establishing temporary holding shelters, special boarding schools dedicated to the protection and education of children with albinism. Such measures had negative impact on their rights to family life, an adequate standard of living and inclusive education (Human Rights Watch, 2016).

3.4 Denied To Form Families

The web of beliefs associated with albinism has a profound influence on the lives of people with this condition, from the moment of their birth until their death, interfering with access to education, employment and marriage (Baker *et al.,* 2010). Persons with albinism are routinely forced to lead their lives single because no one wants to be married to them (Small, 1998). It is obvious that while males with albinism struggle to get wives, female people with albinism also struggle to get husbands but in vain (Magobe, 2008).

In an interview with a single mother with albinism (also a mother to three children with albinism), narrated how her parents divorced few months after her birth. She got three children with albinism whose fathers were not recognized traditionally because she got them out of wedlock. She had no hope of getting married due to her condition. This suggests that she got the children from a fellow person with albinism or from normal looking persons but being a carrier of albinism gene. According to Gaigher *et al.* (2000), the choice of a marriage partner is a serious dilemma for people with albinism.

Findings from a study by Kiprono *et al.* (2012) found that albinism was a reason for divorce in 50% of those who were divorced. Cultural beliefs and lack of awareness on the genetic transmission of albinism make it difficult for people with albinism to establish and maintain relationships. Thus, almost 90% of albinos living in most African regions are raised by single mothers, because the fathers believe their wives have affairs out of the marriages which lead to having children with albinism (Chege, 2012).

3.5 Economically Challenged Life

In some cases PWA decide live lonely life after leaving their households in rural areas taking refuge in towns. In most cases, stigmas attached to PWA affect them in several aspects. In an interview with a person with albinism who lost her job due to being with albinism claimed that:-

> *"I was terminated from work because my boss thought he was not safe anymore by staying in his home with a person with albinism"*

She later started working as a food vendor but she further claims that:-

> *"I worked as a "house maid" for several years in which I could cook nice foods, but when I started "mamalishe" (food vendor) business, I never got clients because of albinism! Finally I closed the business"*.

Several challenges confront people living with albinism's wellbeing. People with albinism are classified among the vulnerable groups of society, who include people living with various kinds of physical disabilities. PWA don't enjoy significant level of attention, security and support from the government. PWA don't get special requirements for PWA which include special healthcare for PWA, advocacy and social awareness education, social inclusion, academic education, economic empowerment, and socio-political protection from various forms of societal abuse and discrimination which are still experienced among people with albinism. Poverty and lack of education suffered by people with albinism result from discrimination, social exclusion and stigma, and in some cases the human rights abuse due to living with albinism.

3.7 Beliefs on Immortality of PWA

Concerning the belief that PWA never dies, all informants did not share the belief that there is any human being who is immortal. These were said to be simple answers to the secrecy surrounded beliefs and practices which were observed upon the death of a person with albinism. A key informant elaborated that:

> "*They actually die as other human beings, but due to the secrecy of where and how they were buried, majority in the community were made to believe that persons with albinism do not die but simply vanish once they finish their missions…*"

Current changes in development accompanied by the adoption of new religions force many people to change their perceptions towards people with albinism. In villages where some houses are modern and built with concrete floors and mostly overcrowded it is not possible to carryout in-house secret burials. Graves for people with albinism are no longer a secret affair to be contained only for few family members, this is said to be among the reasons why some graves for PWA are exhumed.

3.8 PWAs' Grave Robbery

In many parts in the study regions, currently, those who violate the tradition and bury PWA openly in public cemetery for whatever reasons, they find the graves of their deceased dug open and desecrated. A key informant explained that:

> *"Grave robbing is not a new phenomenon in this area that is why albinos were strictly buried secretly… In 1980s I attended a funeral for our fellow Christian in one of the major towns in Lake Zone*

> *who was buried in our church cemetery. The dead body was secretly stolen overnight by unknown people"*

For fear of grave robbers, PWA is currently buried in a cement-sealed grave to protect such graves against grave robbers who often dug open the graves to steal body parts of the dead on witchcraft grounds. Besides being expensive, cement-sealed graves for albinos give a different picture in the society where such graves are uncommon. Such graves confirm the myth that PWA's bodies are extremely valuable such that they should be highly protected.

3.9 Believed Power in PWA's Body Parts

Most powerful "*medicines*" for significant effects are believed to be prepared from most valuable or expensive ingredients. It was mentioned and believed that in order for one to prosper must offer a certain sacrifice. Therefore, witchdoctors in such cases use parts of person with albinism believing that they possess powerful magical power. While people with albinism faced discrimination for many years, their situation has become far more dangerous in recent years due to being targeted by those who kill them for their body organs to be used in luck medicine by people seeking wealth and good fortune in business, professional circles and politics.

3.9.1 PWA's Hairs for Successful Fishing

Concerning use of hairs from persons with albinism in various practices of witchdoctors, all informants agreed that the practice is common in the area. Some witchdoctors were said to require from their clients portions of hairs from PWA as an ingredient in preparation of "*medicine*". A key informant said that:

> *"Fishing is a tiresome work. They meet many challenges in the lake; they must consult witchdoctors for safety and success in their daily activities"*.

Use of mixtures of PWA's hairs with other ingredients woven into fishing nets to increase the catch for some fishermen is therefore common. Witchdoctors are said to demand PWA's hair from their clients in order to prepare the mixture. Together with the "*medicine"* woven on their nets, fishermen wear amulets mostly made from albino's crushed bones. It is then a practice that people with albinism shave their hair and disposes their hair with caution.

3.9.2 PWA's Bones for Fruitful Gold Mines

Use of "*medicine" from* witchdoctors is common in small scale mining. In fact it is very difficult to separate witchcraft beliefs from small scale miners. In most cases accidents which lead to deaths in small scale mines are believed to be sacrifices to gods; therefore, people expect to get more gold after such occasions. Informants said that some miners therefore believe that by burying parts of a PWA`s body at one's mining site, the next step is hammering the gold reef. A key informant informed that:

> *"The bones (from limbs) of an albino attract more gold to the site. After directives (from a witchdoctor), crushed or part of the bone is buried at the site"*.

According to Ackley (2010), the belief in the efficacy of albino body parts for creating success and wealth is so strong that sometimes dead albino bodies are exhumed in order for people to seize any remaining organs on the body. Any "*medicine"* is believed to be ineffective if it will be missing the *"active part"*. Various parts of PWA are used in preparations of the *"active part"* for medicines of specific purposes

3.9.3 PWA’s Nails for Wealth Protection

In the study region, people who believe in magical power from PWA’s body parts, consider the parts being very important making one successful various aspects. They also, believe that money obtained in businesses need to be protected. This is because money obtained can be lost miraculously as how it was earned through believing and practising witchcraft under assistance of witchdoctors. People still consult witchdoctors to safeguard money from being stolen or lost miraculously. Albino nails are believed to be effective in protecting money from devils or demons who are believed to be agents in stealing money from people. A key informant said:

> *“Medicine made from albino nails can bring good luck and hold/protect money/wealth from being grabbed by bad people*”

4.0 Conclusions and Recommendations

4.1 Conclusions

Beliefs related to PWA killings, attacks and discriminations are reinforced by witchcraft beliefs which regard PWA as abnormal beings. Old beliefs regarding people with albinism still exist in the study area. A number of myths and superstitions still surround PWA in which it is believed that their body parts can make solutions against bad luck, poverty, witchcraft and politically in winning in elections. As a result, people with albinism are for long are buried secretly indoors because their body parts are highly demanded. Results also imply that witchcraft belief is still believed to influence people in their daily activities. This implies that culture, being the way of life of a people, is usually very difficult to change it overnight

4.2 Recommendations

It is recommended that, a policy for a long time solution should be formulated to insist on awareness of young generation on albinism. Being marginalized and denied opportunities for employment, people with albinism have very limited marketable skills and trainings. It is recommended therefore that, Local Government Authorities should assist them through capacitating them with entrepreneurship skills. Entrepreneurship skills will provide an alternative way for them and offer increased opportunities to accommodate their challenges and maximize their strengths and skills.

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