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THE SYMPOSIUM THEME: LEVERAGING HIV/AIDS INTERVENTIONS TO PEOPLE WITH DISABILITIES: A SOCIAL JUSTICE PERSPECTIVE

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1. INTRODUCTION

For many years people with albinism have been experiencing dehumanization practices from the community members. These practices are rooted basically from different myths, false believes, inadequate education on albinism and its etiology, and superstitious. These practices end up victimizing people with albinism. Looking for instance, the way people with albinism are named in Swahili “zeru-zeru”. It is these historical perceptions that continue to jeopardize the basic human rights for people with albinism. Many community members do not understand the genetic factors which lead to albinism. Actually, in many societies, there are different kind of believes about people with albinism. For instance, in many community of Tanzania, there is a common myth which says “people with albinism do not die, but at a certain stage in life, they disappear”. A myth or believe as this, shows how people with albinism have been hunted, killed and mutilated for many years. It is very important to note that, for all those years, the Tanzanian
community and government was silent about it. As a result, several organizations at grassroots level, namely: Non-Governmental organizations (NGOs), Community Based Organization (CBOs), Faith Based Organization (FBOs) and the organizations for people living with albinism themselves have taken a lead into lobbying the government to develop programs, policies and strategies with the intention to protect and address pertinent issues of people with albinism.

Due to the existing believes and myth around people with albinism, the socio-economic structure or the mainstream of the economy has excluded them. They are not excluded because of their disablement but due to society’s negative attitude and discrimination of perceiving them as worthless; difficult to handle; unemployable; fools and not capable of doing anything (Jandwa, 2006; Said, 2006).

The issues affecting people with albinism have gained momentum in recent years in Tanzania. As a result the government has responded to their plight, by promulgating a good number of legislative instruments to deal with and address the challenges related to marginalization and the exclusion practices. This notwithstanding, the Legal Human Rights Centre (LHRC, 2009), pointed out a number of shortcomings in such initiatives. The shortcomings include among others; poor learning environment and social security for people with albinism. As a result, due to discrimination and killing practice, people with albinism are not free to access social services and other amenities enjoyed by other citizens.

The importance of inclusion environment cannot be over emphasized. It provides sense of dignity and social security to all human beings. It helps to create a strong self-esteem and confidence which many people with albinism are lacking. It is highlighted that, due to discrimination against people living with albinism, their efforts to access socio-economic services are undermined and as a result, cannot make any advancement; as the results the majority of them are poor and cannot break away from the poverty trap.

This paper is about “the predicament facing people with albinism; turning on the truly sight”. This paper is a desk based review of the available empirical studies conducted globally on issues affecting the welfare of people with albinism. Very important to note, special attention is given to the relationship between the albinism and the infection of HIV/AIDS.
The literature revealed that, the factors which contribute to the killing of people with albinism are many and varied but also interrelated; these include: stigma and society’s negative attitude; poor understanding of albinism itself; greedy of riches, cure for HIV infection, poor understanding of the truth about people with albinism and the ineffectiveness of the available policies and legislative instruments.

2. BACKGROUND INFORMATION

In Tanzania, people with albinism represent one in every 1429 births, a much higher rate than in any other nation. According to Al-ShymaaKway-Geer, an albino member of parliament, there are 6977 officially registered in Tanzania. However, it is believed that there may be up to 17000 undocumented. A number of albinos have migrated to the Dar es Salaam area, as they feel safer in an urban setting.

Tanzania is thought to have the largest population of albinos in Africa. Albinos are especially persecuted in Shinyanga and Mwanza, where witch doctors have promoted a belief in the potential magical and superstitious properties of albinos' body parts.

Geita District is one of the areas with significantly many incidences of albino killing and has an industry in selling albino body parts to miners and fishermen. It is believed that the body parts of people with albinos have magical powers capable of bringing riches if produced by local witchdoctors and used as medicine. This is the genesis of the killings and mutilating of the albinos. According to 2009 Census conducted in Geita District by Geita Commissioners Office, Geita District had a total population of 122 people with albinism.

There are further issues which arise when there is lack of education about albinism. Fathers often suspect the mother of the albino child of infidelity with a white man or that the child is the ghost of a European colonist. This can cause immense strain on families and relationships. An albino child is often seen as a bad omen and treated as unwanted. Many albino babies become victims of infanticide to these superstitious views.
With escalating killings, President Kikwete publicly and repeatedly condemned witch doctors, their helpers and middlemen, and the clients, which include members of the police force, for these murders. Victims include children snatched or abducted from their parents. The killers and their accomplices use hair, arms, legs, skin, eyes, genitals, and blood in rituals or for witch potions.

The United Nations High Commissioner for Human Rights has published a preliminary report regarding discrimination which has been directed toward people with albinism. This report has been submitted as part of the Human Rights Council resolution 23/13 of 13 June 2013. It reinforced that "states would adopt specific measures to protect and preserve the rights to life and security of persons with albinism, as well as their right not to be subject to torture and ill treatment, and ensure their access to adequate health care, employment, education and justice."

The discrimination of albinos is often demonstrated by family members and relatives especially at birth, and ill-treatment by general society is widespread where there are severe issues of social exclusion and stigma. The Resolution 23/13 explains the Human Rights council’s concerns about "attacks against persons with albinism" Therefore the Council encouraged the United Nations High Commissioner for Human Rights (OHCHR) to submit a report. NaviPillay is the current United Nations High Commissioner for Human Rights.

As the representative, on 11 March 2014 she submitted a message which overviewed the current status of discrimination against persons with albinism and possible pathways for change and development in protection of albinos. "People with albinism have the right to live without fear or bullying, discrimination, social exclusion, killing and dismemberment." This footage was published on 13 March 2014 to overview the current situation surrounding albinos who live in fear of being murdered or captured for the purposes of murder medicine and witch doctors belief in the magical potential of albino hair and limbs.

Also a key issue is the influence of educating the public to encourage the removal of the social stigma associated with albinos in a society which does not completely understand that albinism is not a curse or a spiritual ghost, but simply a skin condition. In Zimbabwe for example albinos
have been given the name "sophe" which indicated that, they are possessed by evil spirits and in Tanzania they are known as "nguruwe" meaning pig or "zeru" which means ghost.

3. ALBINISM AS A GENETIC CONDITION

The word Albino means a white person. It is derived from the Latin word “albus” meaning “white”. Since the 17th century the word Albino has been used to describe living creatures with Albinism, having little or no color in the skin, eyes and hair. For humans the term people living with Albinism is preferred by some because it emphasizes that these are people like anybody else who live with a special condition: “Albinism”. We will use both terms interchangeably.

Language can shape ideas and create reality. Therefore, we should avoid using words like “zeruzeru” meaning a double zero or a worthless person. Using this word is very impolite and singles out Albinos in a negative and an unjustified manner. 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. Persons with albinism (PWAs) 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. It is, however, more prevalent in some parts of the world than in others. The gene that carries albinism is a recessive gene or a gene that it is not dominant. The recessive gene for albinism becomes expressed only when two parents carrying the recessive genes pass them to the child.

The albinism gene may ‘hibernate’ for generations only to spring back when a child who carries the recessive genes is born. There are several classes, types and sub-types of albinism defined by level of lack of melanin and body parts affected.

4. INHERITANCE OF ALBINISM

Most children with Albinism are born to parents who have normal hair and eye color for their ethnic backgrounds. This is due to the fact that, the body has two sets of genes (one from the mother, one from the father), a person may have normal pigmentation but carry the Albinism gene. 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 pigment.

The Albinism gene is “recessive” which means that it does not result in Albinism unless a person has two genes for Albinism. When both parents carry the gene, and neither parent 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.

5. PERSON WITH ALBINISM AND HIV/AIDS INFECTION

Some people believe that people with albinism cannot get infected with HIV. This quite untrue because people with albinism are normal persons like others. The only different is that they lack melanin, a pigment responsible for the color of the skin. The chance of getting infected is the same as for anybody else if in contact with body fluids from a person with HIV. This is most likely to happen during unprotected sexual intercourse.

Other people believe that people with albinism do not have HIV. This also is absolutely not true. This may be an intentional distortion of the facts by a few members of society to propagate such wrong beliefs. People are willing to believe all possible mistaken ideas in order not to face the truth about HIV. They hope to find a cure by having sex with a virgin, with a disabled person, with a person living with Albinism. All this is non-sense.

HIV is a virus transmitted through body fluids and especially through unprotected sex. The only secure way is to use a condom or for both sexual partners to be tested and to be faithful to each other. However, this is exactly what those people who spread rumors deny. They are searching for an easy way out.

People are willing to believe all sorts of mistaken ideas in order not to face the truth about HIV. They hope to find a cure by having sex with a virgin, with a disabled person or, with a person living with Albinism. All this is non-sense. The myth that one can be cured of AIDS by having sexual intercourse with an Albino is not true. Up to now there is no known cure for AIDS, although there has been great progress made in developing treatment with drugs called ARVs
(Antiretrovirals). These drugs have greatly improved the lives of people living with the virus. However, these drugs do not cure the disease. Therefore once someone becomes infected with HIV they will remain infected for life and they will not be cured by having sex with an Albino.

These myths also affect other groups in society, for example some people believe that having sexual intercourse with a virgin can cure AIDS. Those false myths have resulted into cases of child rape. It is important for young Albinos to know the truth and to protect themselves accordingly. The myth that having sex with a woman with albinism can cure HIV/AIDS has fueled this form of violence. The shocking trend has left the victims contracting HIV which complicates their health and psychosocial condition. For women and girls with albinism, sexual violence makes theirs a case of multiple tragedies; women rights are yet to be realized in largely patriarchal traditional communities; further, being born with albinism means stigma from birth which is normally accompanied by skin and sight problems and poverty.

It equally important to note that, women with albinism are being targeted for ritual rape as a cure for HIV/AIDS, and the infections that follow, only aggravates the situation of the victims and this calls for urgent action from governments, communities and international actors. Defilement and rape are infringements on the dignity of a woman and an abuse of the rights to safety and security of the person.

Psychologically and physically, women with albinism are likely to be more vulnerable to predatory men, but the consequences are far-reaching, as AIDS is transmitted to husbands and children. A man with albinism in Zimbabwe acknowledges this: to be an albino is a terrible thing, but to be a girl albino is the worst of all. You know that the AIDS pandemic, they say the cure is to sleep with a virgin, but if you sleep with a virgin who is albino then even better. There are many rapes. Because they are so hidden already they do not come forward. And now because of this we are also dying of AIDS. This rape it is a terrible thing.
As far as infection with HIV is concerned there is no difference between people with Albinism and other infected people. They get it by the same modes of transmission and they have the same need for social, psychological and medical support. They get the ARVs if needed and under the same conditions as anybody else.

When they face a problem getting their service, should address a community leader or a member of the Albino society to successfully claim their rights. There is no special hospital for people with Albinism who are living with the virus, but there are specialized hospitals to care for the specific problems of people living with Albinism. Those hospitals are specialized for early diagnosis of skin cancer (like Ocean Road hospital in Dar es Salam and KCMC in Moshi or like CCBRT for vision problems in Dar es Salaam).

6. CONCEPTUAL FRAMEWORK

This work on “The Predicament Facing People with Albinism; Turning on the Truly Sight” is informed and guided by the “Social Model of Disability” and “Human Right Approach”

Social Model of Disability

The Social Model of Disability was given an academic credit through the work of Vic Finkelstein. Mike Oliver is therefore seen as a proponent of the approach. Later, the Social model of disability was adopted by other countries and extended to include all people living with disabilities.

Social Model of Disability is based on the distinction between the terms “Impairment” and “Disability”. Impairment is defined as lacking part or all of a limb, or having a defective limb, organ or mechanism of the body. It is considered therefore as a personal identity and a medical condition of such individual. On the other hand, Disability is defined as the disadvantage or restriction of activity caused by a contemporary social organisation which takes little or no account of people who have physical impairments and thus excludes them from participation in the mainstream of social activities.
The Social Model of Disability argues that, although individuals may have various limitations in terms of their impairments, the degree and nature of the disability, their experiences will be the result of the society’s arrangements which do not support their social, economic and cultural participation. Further, the Social model of Disability was deemed sufficient to guide and inform this work entitled “The Predicament Facing People with Albinism; Turning on the Truly Sight” : this is due to the fact that, the approach was developed by people living with disabilities and were determined to see the changes and shift in the way society is constructed and organised. As a result, people living with albinism are denied their human dignity. People with albinism and Social worker in Tanzania can therefore apply this approach to lobby and advocate for the government to create a respectful and meaningful living environment for them.

People with albinism are disabled by the fact that, are discriminated, hunted and killed due to myths and believe of some community member. Their human dignity is jeopardized by the greedy of few individual.

**Human Right Approach**

The Constitution of URT recognizes the right to life as a basic for every citizen. Denying any member of the society such right is against his or her fundamental right. Further, due to fear, people with albinism have no freedom of movement, majority of them are confined in home where they feel are safe. This is against the human right which is recognized by the constitution.

### 7. CHALLENGES FACED BY PEOPLE WITH ALBINISM AND THEIR FAMILIES

i) **Social stigma and derogatory name-calling leading to prejudice and discrimination:**

In many parts of the world, persons with albinism are largely seen as being incomplete. The use of derogatory names for persons with albinism has led to prejudice and stereotypes which lead communities to condemn them based on the condition rather than appreciate their humanity first.
In East Africa, most of the descriptive terms used to refer to persons with the condition are derogatory and demeaning. They seem to suggest a lesser being. In Kiswahili, a language spoken by millions in East Africa, the name for persons with albinism is ZeruZeru meaning ‘ghost like creature’ while others refer to them as ‘mzungu’ meaning ‘white man’.

ii) Gender-based sexual violence:
The myth that having sex with a woman with albinism can cure HIV/AIDS has fueled this form of violence. The shocking trend has left the victims contracting HIV which complicates their health and psychosocial condition. Women with albinism are being targeted for ritual rape as a cure for HIV/AIDS, and the infection that follow, only aggravates the situation of the victims and this calls for urgent action from governments, communities and international actors. Defilement and rape are infringements on the dignity of a woman and an abuse of the rights to safety and security of the person.

iii) Killings and harvesting of body organs:
Recently, killings of persons with albinism in East Africa and southern Africa, especially in Tanzania, have woken up the world to the threats facing people with the condition. Reports from various sources indicate that about 100 persons with albinism may have been killed in Tanzania and Burundi in the past few years. The killings are done in order to harvest body parts which are used in making of charms by traditional witch doctors.

It is believed that charms made with body parts of persons with albinism, especially hair, genitals, limbs, breasts, fingers, the tongue and blood make strong magic portions which sell for more. In Tanzania, organs can go for a high price. Mr Ash of UTSS says, “a leg or an arm can fetch between US$1,000 and US$3,000 — big money in a country where the annual average income is just $800”

iv) Lack of appropriate medical attention:
Because of lack of melanin pigment, persons with albinism are pre-disposed to health problems of the skin and vision. Skin cancer cases are higher in persons with albinism due to the effect of ultra violet rays from the sun which causes lesions. To lessen the effects of the sun, persons with albinism need to apply sunscreens, wear hats and use special sunglasses which are costly and in most rural areas, unavailable. Many governments have failed to ensure access and affordability of these vital items. The national health systems have failed to factor in the needs of persons with albinism adequately.

v) **Discrimination in employment:**
Persons with albinism are routinely shunned from employment by both private employers and governments due to their condition. They are thought of as being incapable or as being a burden. Sometimes, they are employed but assigned tasks that require them to work for a long time in the sun which exposes them to the risk of developing skin cancer.

vi) **Discrimination in education systems:**
For years, learning institutions in Africa have put students with albinism under the same conditions as other students without taking into account the visual impairment associated with the condition. Poor vision may cause students with albinism to be slow learners either due to inability to see the black board clearly or inability to read books and other learning materials. The colours used in writing also matter because students with albinism have a problem with contrast. The text books and exam papers are mostly printed in normal fonts which may be hard for students with albinism to read quickly.

Students with albinism have also been required to finish exams at the same time as other pigmented students whose sight is normal. These conditions have led to poor academic performances and low education levels for persons with albinism. This in turn denies them livelihood options hence the abject poverty that many live in. Lack of education and life skills also limits their active participation in local, national and international affairs.

vii) **Attacks on persons protecting/defending persons with albinism:**
Many persons, especially family members have been harmed or even been killed while trying to stop attacks on persons with albinism. Cases have been recorded from Tanzania and Burundi where attackers brutalized family members of persons with albinism.

**SOCIAL WORKER EXPECTED INTERVENTIONS**

- People with Albinism are excluded from education system due to the fact that, their sight cannot have access to the blackboard. Giving them the front row seat still in it is not the only solution to include them into the system. However, social workers have to undertake the sign language so that can use it to reach them. Further, the review and preparation of social work curriculum at all levels of education, have to include the sign language in order to produce social workers who compete with sign language skills.

- Since the first report of the killing of people with albino, there no stand or position taken by social worker, being an individual or an organization condemning it. Other organization declared their position, some of them organized demonstration. The keep slight among social worker over these sensitive issues makes the profession an invisible. The advocacy should be used to stand for people with albino. The mass media can be used to reach the public. TASWO using its platform can organize solidarity demonstration against any form of discrimination against people with albinism.

- Education is a vital tool that can be used to transform the public over the available misconception about people with albinism. Social workers as resourceful personnel at all level of interventions, have to be informed about people with albinism so that may take the truly role to impart knowledge to the community members.

- As the agents of change, social workers can take an effective role of gathering information about people with albinism at the grass root level. This may include, getting their number at village, ward and district level. This process would help to strengthen the social welfare system during allocation of resource. Remember, the number of people
with albinism is still not known exactly. This impact negatively on the planning and allocation of resources logistics. A contribution of this kindly, would be appreciated not only by the people with albinism but also the general public as well as the international community.

➢ There is a need to conduct a critical study on the strategy available to curb the killing of people with albinism. Social workers should take a lead in this kind of study so that the policy makers can be informed of the strength and weakness of the available legal instruments into addressing the predicament facing them. The review of the strategies may include; the session on the tradition healing practices, the policy on people living with disabilities of 2004, the constitution of the URT 1977 and the Human right protection conventions to list a few.

➢ Social workers have to organize fundraising program which can be used as source for funds. These funds can then be used to purchase skin lotion which prevents skin cancer. Further, social workers can take a lead into writing proposals to different donors who are willing to support these efforts of helping people with albinism to live a meaningful life.

➢ Social workers have to organize and conduct sustained education of the general population, including those in the medical profession, through all media on the genetic condition of albinism and HIV/AIDS and how to integrate persons with albinism in mainstream society as well as to deal with stigma and myths that lead to prejudice and discrimination.

➢ Social workers need to organize and conduct awareness campaigns, particularly in severely affected areas like lake zone so that the community can get more knowledge about albinism and can be better organized and strengthened to prevent and mitigate albino killings.

➢ Social workers may conduct capacity building training strategies for people with albinism to reduce their vulnerability
Most people with albinism are in fear of violence and therefore stay at home as much as possible. These people and their families therefore lack time to engage in gainful activities. Social workers should plan to support these families and make sure the children could go to school.

SPECIFIC SOCIAL WORK INTERVENTIONS

- Rape cases among people with albinism; social worker should educated the community about the reality of being albinos and HIV/AIDS
- People with albinism are prone to HIV/AIDS infection; Social workers should initiate programs that educated them to practice safe sex.
- Myths & Believes on HIV/AIDS cure: Social workers should involve traditional healers in the process of transforming peoples myth and believes about HIV/AIDS cure.
- Visibility of letters written on Condom; Social workers should advocates for big letters to be used on the condom

Conclusion/ Summary

The murders, amputations and trafficking in body parts of persons with albinism in parts of East and southern Africa is an affront to the dignity and sanctity of the human body as guaranteed under international human rights law. Those laws assert and presume that human beings are born free and equal in dignity. Myths surrounding the genetic condition of albinism persist in many parts of sub-Saharan Africa. Superstition in some communities has led to the belief that persons with albinism either possess some special powers or are incomplete.

Lack of sound knowledge on the condition has led to discrimination and stigma. States and communities have consistently neglected and shunned persons with albinism in employment and education. Their health status is largely overlooked by the healthcare systems. Persons with albinism deserve the same dignity as pigmented persons and states have the obligations to
respect, protect and fulfill their rights. They also have the duty to extend some special rights to persons with albinism in the form of affirmative action in order to integrate them into mainstream society and to ensure that they live their lives in dignity. Social workers as change agents has a great role to play to make sure that people with albinism live a joyful life in their countries as other people without albinism live.
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