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NAME CALLING, FEAR AND KILLINGS: CHALLENGES FACED BY PRIMARY SCHOOL PUPILS WITH ALBINISM IN MISUNGWI DISTRICT, MWANZA – TANZANIA

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Abstract: *People with albinism in Tanzania encounter multiple challenges due to their physical condition which hinders them from achieving their desired goals in life. This Study sought to investigate the challenges which pupils with albinism face and possible measures to combat the identified challenges. A qualitative approach and critical ethnographic research designs were adopted for this study. In making sense of our findings, we were guided by the “theory of stigma” by Goffman 1963 which is based on discrediting attributes. To affirm stigma, Goffman explains the stages of stigmatization which include: labeling human differences; stereotyping such differences; separating those labeled from “us”; and status loss and discrimination against those labeled. Participants were obtained from one primary school which we selected purposefully because of its large number of pupils with albinism. Participants included; 3 teachers, 1 head of the school, 10 pupils with albinism and 1 patron responsible for pupils with albinism in the school. Data was collected through in-depth interviews and open ended questionnaires. The findings from this study indicate that majority of pupils with albinism experienced multiple challenges which we categorized into three groups. First, health challenges which include; poor vision, lack of balanced diet, lack of reliable safe source of water and scarcity of protective devices. Second, social psychological challenges which include; abandonment, not being loved, stereotypes, worries/fear, uncertainties and the like. Third academic challenges which include; poor vision, inability to read, overcrowded classroom and lack of learning resources. Based on these findings we concluded that, stigma and discrimination still exists among pupils with albinism. This situation should not be tolerated as it amounts to human rights abuse and if unattended it may progress to loss of innocent lives. Recommendation to improve this state of affairs are directed to the government, educational policy makers, educators, families, and societies at large. All these stakeholders should strive towards creating and ensuring favorable school environment for pupils with albinism.*

Key terms: *Name calling, killings, experiences, fear, stigma, albinism and human rights*

1.1 Study Background

In Tanzania, like many other African countries, people with albinism have experienced unbearable and continuous discrimination leading to persecution, abduction, violence, marginalization, extreme fear and killings. This situation affects people with albinism of all ages including school children. The reason, behind such in human acts is not exactly known. However, lack of understanding of the courses of albinism may have led to irrational beliefs leading to persecution of these innocent people. For this reason, it is important that we begin this paper by bringing to light the understanding of what course albinism in humans, the magnitude of the problem and how such people are being treated by other humans. As a condition which results from genetics, Albinism is known as achromia, achromasia, or achromatosis and not a new phenomenon (Nordqvist, 2014). According to Hong, Zeeb and Repacholi (2011), albinism is categorized in two types: *Tyrosinase* negative *Oculocutaneous* albinism (OCA1) where there is little or no melanin production due to the lack of a functional *Tyrosinase*, and the critical enzyme required in the melanin biosynthetic pathway and *Tyrosinase* positive (OCA2) where OCA2 there is some level of *Tyrosinase* activity, thereby producing some red-yellow photo melanin pigment that gives rise to sandy colored hair and light brown irises. This hereditary disease can be found in humans (affecting all races), mammals, birds, fish, reptiles and amphibians (Nordqvist, 2014).

According to Uromi (2014) as directly reported “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. In Denmark, the prevalence is estimated at a ratio of 1: 60,000. In parts of Nigeria, the prevalence is put at 1: 1,100 while in South Africa it is estimated at 1: 3,900. In Tanzania it is estimated that the prevalence stands at around 1:3,000. Estimates for Tanzania quote the total population of persons with albinism at about 170,000”

According to the United Nations (2006), a study assessing prison life of disabled people in Ghana, albinism was named specifically as one of six categories of disability. These categories of people have been accorded human rights as any other person in our society. These rights include a right to life, adequate standards of living and social protection, equality and non-discrimination, freedom from exploitation, violence and abuse, and a right to education, health, work and employment.

A large number of people with albinism are found in the African continent (Lapidos, 2009). Majority of people with albinism in Africa are exposed to poverty, due to that fact there must be quick intervention to help this group of people because the special care they need is costly. African has had some of the highest number of attacks among the people living with Albinism. These attacks included but not limited to: - mutilated persons; those who narrowly escaped an attack; missing persons and successful asylum cases. Among those countries with highest prevalence of these cases include: Tanzania (139), Burundi (28), Democratic republic of Congo (27), Ivory Coast (21) and Kenya (12) (UN CRC, 2014).

On children with albinism in Lund's study (1998) in Zimbabwe, only 23% of her sample had ever had their skin examined by a health professional and this was often only when they were babies. In terms of other health needs, less than half in this sample (46%) had been to a hospital or private optician for an eye test and only 27% had prescription glasses, 5% of who felt that they did not improve their eyesight.

The Burundi Red Cross (Red Cross branch in Ruyigi Province, where the first albino killings in Burundi occurred in August 2008) has been instrumental in coordinating a spontaneous humanitarian response there; those involved include local NGOs, UN staff, churches and schools. They collected food, clothes and cash that people had donated personally. The branch in Ruyigi is now scoping a major humanitarian intervention in the albino crisis, which is intended to promote their long-term reintegration into society and reduce the atmosphere of vulnerability around them. "We're forming a donor partnership with the World Lutheran Federation," says JeanPierre Sinzumunsi, Burundi Red Cross regional coordinator for Ruyigi and Cankuzo provinces. "We want to help our volunteers better understand the problems of albinism, and to promote the integration and protection of albinos. "We also aim to sensitize the local authorities, the police, the military, priests, local NGOs and village elders" (IFRC&RCS, 2009).

A study carried out in Tanzania showed that, respondents did praise the government's awareness campaigns, which are viewed as the main reason for an improvement in attitudes towards people with Albinism. In the 2 years following 2008 when the Tanzanian government declared it a capital crime to kill people with albinism, more than 170 people were arrested. However, very few were prosecuted, with courts citing a lack of funds for litigation as the reason (Bucaro, 2010). The situation seems little changed since that study. In response to the extreme violence against children with albinism, the Tanzanian government implemented a policy of moving children with albinism from their family homes into special schools and camps in order to protect them (Burke, Kaijage, John-Langba, 2014). It is argued that while emergency response might have increased security, concerns were raised about overcrowding, inadequate facilities and support, incidents of child abuse and family members abandoning their children in the facilities (Burke, Kaijage, John-Langba, 2014). The impact of this form of segregation on family life has received less attention and even less so the impact on the wellbeing of the children.

In a thesis report undertaken by Stensson (2009) on Social stratification among Albino people in lake region, Tanzania, there were more at least 686 albinos killed from the year 2002 to 2009 according to the Secretary General of the Albino Society of Tanzania, Samweli Mluge. They were killed because of witchcraft and superstitions. Furthermore, people with albinism are also overwhelmed with fear and have complained about people who ridicule them.

1.2 Statement of the Problem

Learning institutions, the community and the society at large have the responsibility to ensure safety and protection of children in and outside the school environment. In Misungwi district, Mwanza region, Tanzania, the situation is not the same especially for children who have albino condition. The society has not fully appreciated them and they are seen as outcast. Whereas this is a condition of genetically altered skin pigmentation, a number of citizens still believe on myths and misconceptions when it comes social interaction with children with albinism. Pointedly, the experiences and perceptions of children with albinism are underexplored and little is known about the psychosocial issues facing them in Misungwi district schools. Several scholars like, Nordqvist

(2015); Hong, Zeeb and Repacholi (2006); Uromi (2014); Ntinda (2008); Allen (2011); Lund and Gaigher (2000); Ndomondo (2015) to mention a few have researched and written a lot on the issue of people with albinism and the challenges they face. However, little is known on the challenges which children with albinism face in primary schools. Hence, it is for this reason that the current research sought to investigate the kind of challenges which pupils with albinism experience in Misungwi primary schools.

1.3 Study Objectives

The broad objective of this study was to investigate on the experiences of primary school pupils with albinism in Misungwi District, Mwanza region.

Specific objectives

- a) To examine the kind of challenges that primary school pupils with albinism face in Misungwi District.
- b) To explore measures that can be taken to improve the learning environment for primary school pupils with albinism in Misungwi District.

1.4 Study Significance

After writing this paper, the researchers felt that, this study may be important in both the development of science and the society. In the development of science, this work through open publishing will be accessible to those doing similar studies as a source of study background and literature. For the development of the society, those doing baseline surveys can access information to develop their proposals and interventions. Again, the true picture on the experiences and challenges facing children living with albino will be properly understood by child care givers. At the policy level, this research may be useful to the policy makers on what can work among vulnerable children in our society.

1.5 Literature Review

Different scholars have written about stigma and discrimination from different perspectives. In this paper, sociological perspective on stigma and discrimination among albino children in the study area is clarified. Theoretical gap in relation to Goffman's work is also explained. Empirical literature review related to the themes of the study is also presented as well as study gaps. The literature was important in bringing academic interpretation and understanding of the qualitative data collected by the researchers from the field. This research was carried out in the year 2016, however some literature was reviewed in the year 2021.

Theoretical Literature Review

The "*Theory of Stigma*" was proposed by Erving Goffman in 1963. Stigma is an attribute that conveys devalued stereotypes. Goffman (1963) classically defined stigma as an "attribute that is deeply discrediting." A discredited attribute could be readily discernable, such as one's skin color or body size, or could be hidden but nonetheless discreditable if revealed, such as one's criminal record or struggles with mental illness. Researchers have enumerated numerous coping responses such as avoidance, suppression, and identity development and have identified these responses' inconsistent moderating effects on stress. Sociologists and Psychologist have different views on the application of this theory. Sociologists use the theory on social phenomenon and rarely not around stigma and social process. Drawing on Goffman but incorporating a broader concern for the operation of power in society, Link and Phelan define stigma as the co-occurrence of four

processes: (i) labeling human differences; (ii) stereotyping such differences; (iii) separating those labeled from “us”; and (iv) status loss and discrimination against those labeled. By incorporating the role of power and dis It is argued that while emergency response might have increased security, concerns were raised about overcrowding, inadequate facilities and support, incidents of child abuse and family members abandoning their children in the facilities crimination in their definition of stigma, Link and Phelan articulated an approach to stigma that would enable scholars to consider how stigma related to fundamental sociological and psychological questions, namely those relating to the social creation, reproduction, and consequences of social inequalities. Albino children in the study area face abuses due to the myths, prejudices and stereotypes attributed to them by some members of the society. This leads to either positive or negative discrimination and builds stigma against them. Name callings, inflicted fear and human right abuses results because of the stratifications arising from the social exclusion. From Goffman’s work, however, experiences of children in a school environment was not presented. The theory did not explain experiences of children in institutionalized environment as well. The theory however explains why people are stigmatized and discriminated as is the case of Children with albinism.

Empirical Literature Review

Physical health challenges: Empirical studies conducted in Tanzania, South Africa, Nigeria and Zimbabwe concluded that, people with albinism are challenged differently including being susceptible to harmful effects of ultraviolet radiation exposure which leads to decreased visual acuity and sometimes skin problems (Hong, Zeeb & Lepacholi, 2006). People with albinism are urged to put on long sleeved clothes and sun glasses to avoid sun light radiation effects to their eyes and skin. Ndomondo (2015) notes that most of the pupils with albinism have visual impairment. Persons with albinism can distinguish colors, but their vision typically lack accuracy. Burke (2012), in his empirical study in Grate Lake Regions found out that, people with albinism are disabled in terms of low vision and sometimes blindness. Moe (2011) noted that, severe visual conditions may force students to drop out of school. Considering these reviews, primary school pupils with albinism need proper health care like regular checkups, skin clinics, vision aids as well as guidance on dressing.

According to Burke (2012), people with albinism in Great Lake Regions are susceptible to skin cancers. Further, he asserts, Skin cancer is a common challenge to persons with albinism. From Burke’s work, most African countries are within the tropics and therefore receive 8 hours a day of solar radiation intensity; therefore, people with albinism within the continent are likely to suffer from skin cancer than other parts of the world with few hours of intense sunlight a day. Allen (2010), in an empirical study conducted in Uganda found out that because people with albinism’s skin lacks the ability to create melanin, the risk of skin cancer is a very serious threat in a country situated on the equator. Primary school pupils with albinism in Tanzanian schools are likely to suffer from skin cancer if not well taken care of due to long hours of sun exposure without protection. Albinism children are likely to suffer from skin moles. These moles result from sun burns if children are not well protected. Tanzania German Programme on health support (2009) noted that: - “The skin of people living with Albinism has almost no way to protect itself against the rays of the sun. It burns badly after long exposure to the sun and the skin itches and hurts. The skin of an Albino tries its best to protect the body from the rays but as it has only small quantities of pigments it can only create some dark spots (moles). Therefore, the dark spots are a sign that the skin is not well enough protected from the sun (p. 18). Primary school pupils with albinism

with their care takers therefore, needs to be well protected, educated and given protection to prevent the effects of sun rays.

In Tanzania, prevalence of albino cancer patients among men and boys were higher compared to those of girls and women with Albino. According to researchers in the Cancer institute in Tanzania, this was aggravated by the vulnerability of men (outdoor working conditions) and the kind of leisure activities undertaken by boys. Furthermore, lack of health facilities and health programmes, including screening and treatment, or inability to afford the health care services directly contribute to the high mortality and morbidity rates of persons with albinism owing to skin cancer (UN, 2017) This notwithstanding, the researcher had own perspective on health care behavior among the different gender. Most of Lake Zone communities are patriarchal. Men and boys might be prioritized by their families as recipients of medical attention in the place of women.

On the psychological challenges: There is a growing acknowledgment and recognition in Africa that people with albinism should be considered disabled. It is Important and essential to understand the socio-structural barriers and restrictions that exclude disabled people (barriers to doing); and the social processes and practices which can negatively affect their psycho-emotional wellbeing (barriers to being) (Franklin, Lund, Bradbury-Jones and Taylor, 2018). A qualitative study with 15 participants (aged 18– 48 years) in South Africa illustrated that people with albinism want to eradicate myths and misconceptions, lobby for their rights and be treated with dignity and equality. The study suggested that the role of albinism advocacy groups was valued by those accessing them. In particular, the provision of services such as counselling and raising awareness had enhanced self-esteem and a sense of empowerment. Advocacy was also seen as crucial in influencing the media, NGOs and governments (Pooe-Moneymore, Mavundla, Christianson, 2012).

As earlier asserted in the study background by Burke, Kaijage and John-langba (2014), the government of Tanzania had established protection centers for albino Children to protect and care for them. An advocacy brochure by Pedneult and Libaki(2019) entitled “It Felt Like A Punishment”: Growing Up with Albinism in Tanzania , however unveiled the challenges the institutionalized children went through before and after. When the killings began, some children were immediately told to stop school by their teachers and others were involved in child labour against their will. Children were given names for example “*Chinese*”, “*Mbulimwelu*” “meaning white goat”. The government directed the district and community leaders to bring in Albino Children to the established “Temporary holding shelters” – special boarding school for their protection and education. An interview with a rights watch group contacted to children, their family members, education professionals and NGO representatives in Mwanza and Simiyu regions in Tanzania found out that, “Tanzanian government policies designed to protect children with albinism incidentally had a negative impact on their rights to family life, an adequate standard of living and inclusive education. In order to protect their privacy and shield them from potential repercussions, the names of most interviewees referred to hereafter have been changed. While the Tanzanian government appears sensitive to these concerns, it should now intensify efforts to reinsert children with albinism into their communities and provide them with inclusive education, while continuing to investigate and prosecute those responsible for attacking children with albinism. By doing so, Tanzania has an opportunity to emerge as a strong African leader in ensuring the safety, inclusion and dignity of people with albinism, as outlined in the Regional

Action Plan on Albinism in Africa, the first-ever continental strategy to address violations against people with albinism, adopted in 2017” (Burke, Kajjage and John-langba, 2014).

In Tanzania people with albinism are tormented psychologically due to different misconception of their condition by the communities around them as explained in Goffman’s theory on stigma (1963). People with albinism are seen as sorcerers, devils or persons suffering from a curse and, in some communities, it is believed that contact with them will bring bad luck, sickness or death (Uromi, 2014). Despite the rule of the law and human rights activism against this vice, people with albinism suffer a lot of stigma and discrimination from the society which should be protecting them. Masanja, Mvena and Kayunze (2014) noted that in many developing nations including Tanzania, persons with disabilities continue to be less valued, dehumanized, and rejected. People with albinism encountered stigmatization and rejection from their own community members (Gaigher, Lund & Makuya, 2002).

Witchcraft and superstition practice in Tanzania has made albino people live in a lot of fear in Tanzania. Tebbe (2007:190) in Mulemi and Ndolo (2014) explained witchcraft as use of magical powers to spell bad outcomes or reaction on others or their negative schemes. On the other hand, Bonerjea (1927) and Mulemi (2004) in Mulemi and Ndolo’s (2014) work on “Albinism, Witchcraft, and Superstition in East Africa: Exploration of Bio-cultural Exclusion and Livelihood Vulnerability” defined superstition as an irrational notion regarding supernatural powers that could alter either man-made and or natural realities. Moe (2011), speaks of a girl, 17 years old who was chopped off all her limbs by some unknown men and fled. Witchcraft practices are shocking because everything in a body of a person with albinism is considered to be “valuable” to the witch doctors; this includes their hair, nails, limbs, even the remains of the dead albino’s body. Moe (2011) established that, even when a person with albinism dies it is not surprising to find a grave robbing problem and sometimes the albinos’ bodies are buried in concrete to avoid their body parts from being exhumed from the graves. Myths are also another social psychological problem encountered by people with albinism and their relatives. The study conducted by Lynch and Lund (2011), discovered that people in Malawi have a belief that people with albinism do not die a natural death but rather disappear in air. This issue of people thinking that people with albinism vanish is very common even among Tanzanian societies.

Tanzanians in different occasions have commonly been naming people with albinism as “*zeruzeru*” and “*mzungu*” (meaning a white man), recently after the outbreak of hunting people with albinism, they have been named “*dili*” (a street word meaning wealth). In other African countries people with albinism have also been given names such as; “*mbunzu gozo*” (black eater of manioc) from Sangho language found in Congo, “*gomblè*” (red man) among the Bamana and Maninka of Mali (Brocco, 2015, p. 5). Brocco also adds that; people with albinism are named “*mzungu*” (white man, European) and “*napwere*” (which refers to a pea-brownish color) in Malawi. The name callings have been psychologically affecting all people with albinism including primary school pupils with albinism. Worse enough people with albinism in Tanzania do not want to be named “*Zeruzeru*” but rather “*watu wenye ualbino*” meaning people with albinism, but the Institute of Kiswahili Research, University of Dar Es Salaam in their English- Swahili Dictionary of 2000 still gives meaning of albino as “*zeruzeru*”, the same is the meaning with Google translate Swahili to English where “*zeruzeru*” means albino. Name callings as such may lead to pupils with

albinism have a discomfort to interact with their community and worsening their academic life because of lack of self-esteem.

Within only one month of June, 2009 in Sukuma Land located in North West Tanzania 48 people with albinism were killed in search for their body parts to be used in superstition activities (Tanner, 2010). People with albinism still live with fear due to continued killings, exhuming bodies of deceased people with albinism from their graves. Moreover, kidnappings and chopping off limbs of people with albinism is still common. Under the Same Sun (2016), reported a baby boy's body being exhumed from the grave in May, 2016. These threatening activities have led to the government and Non-Governmental Organizations to create centers for securing people with albinism who can no longer live freely like any other human beings due to fear for the continued hunts and killings.

Stress and low self-esteem are hindrances to pupils with albinism prosperity in their day to day life but also in their academic journey. Majority of pupils with albinism sometimes are traumatized because in most cases they are isolated by their very own care takers and parents, it is because of this that their life is full of doubts leading to them lacking confidence in almost everything they try to do including their academic activities. Newman (2016), observed that people with albinism, due to their differences in skin color pigmentation, they are sometimes bullied and this leads to stress and isolations.

Academic Challenges: In their pursuit to get education, people with albinism are challenged within and outside academic institutions. The stigma and discrimination encountered by this group of people threaten their academic performance in many ways. Teachers, managers, educational supervisors and community members are still not knowledgeable of the needs and wants of pupils with albinism (Ndomondo, 2015). The Tanzanian Albinism Society reports as sighted by Nicopolis Ltd (2016) that: "A very high number of children with albinism are dropping out from schools because of the intense discrimination that they face within the 'inclusive education' systems. A very large proportion of these children are suffering from rejection, anxiety, fear, post traumatic disorders and sexual abuse due to superstitious beliefs in Tanzania that if one sleeps with a person with albinism, one can get cured from HIV."

Lack of books with large prints is also a challenge to most schools which have pupils with albinism (Ndomondo, 2014). By looking at the health challenges, social psychological and the academic challenges all of them affect the learning of a student with albinism because all of them contribute to the discomfort to the student.

Measures to improve the situation: The need for increased awareness of public health interventions for albinism is crucial in order to better address the medical, psychological and social needs of this vulnerable population (Hong, Zeeb and Repacholi, 2006). Every child born with albinism is automatically born with low vision and this becomes a challenge from early child hood stages to the rest of his or her life. Parents and care takers should therefore make sure they seek medical help so as to minimize eye problems. Lund and Ghaiger (2000), in a study titled "A health intervention programme for children with albinism at a special school in South Africa" suggests that many eye problems that pupils with albinism encounter can be improved, by wearing tinted or dark glasses to help reduce glare and prescriptions to improve refractive errors. Newman (2014,

p. 1) also suggests that: “Surgery on the optical muscles can sometimes minimize the "shaking" in nystagmus.”

Skin cancer is also a disease challenging most people with albinism. Majority of people with albinism are susceptible to skin cancer due to their skin having no ability to protect them against direct ultraviolet radiation from the sun. Skin cancer to people with albinism can be prevented by regular medical checkups and education on protection. Primary school pupils with albinism should be provided with hats, protective skin lotions and long sleeve clothes. Parents and care takers of primary school pupils with albinism should be responsible to make sure that these children are taken for medical checkup. This could be done at least once per month so that if they are diagnosed of cancer, early treatment can be initiated. Mabula et al., (2012), comments that surgery is the best treatment for skin cancer to people with albinism. The same study also found that “*good results can be obtained with radical surgery and optimal surgical margins along with reconstructive procedure when needed in most African continent where sun takes a long time*” (Mabula, et al, p.6).

Social Psychological Measures: Educating citizens on human rights challenges including social marginalization, medical and psychological problems, and confinement to poverty affecting people with albinism is indispensable (McAthur,2015). Ignorance of albinism and misconception among majority of people living with albinism has led to a lot of killings, stereotypes, torture, discomfort and fear among people with albinism with their loved ones. It is the high time that people are educated on the issue of albinism and how to protect themselves against any harm. Tanzania is also one among many countries in the world who has signed an International Convention of the protection and promotion of the rights and dignity of persons with disabilities of 2006 (Tanzania German Programme to support Health, 2009). The law of protecting children living with albinism should apply to all. Strict measures should be taken against those violating laws.

Academic Measures: For a pupil with albinism to learn better, the school environment should be conducive enough for them to study comfortably, for example, proper accommodation, good classes, qualified teachers and friendly school community. The National Organization for Albinism and Hypo pigmentation “NOAH” (2002), found that one of the best solutions to help pupils with albinism was moving the child’s seat to the front row so the student can see the chalkboard, marker board, overhead projector, or video. Changing where a child with albinism sits can help to avoid glare from overhead lights or windows. A child with albinism should be allowed to copy from overhead projector and if the child can’t see the projected overhead be assisted with notes, or enlarge texts and handouts (NOAH, 2012). Ndomondo (2015), on the other hand suggests that there should be a curriculum review in all levels of teacher education in the nation in order to incorporate aspects of inclusive education from giving out the special education to only few teachers. It is very essential for teachers especially those teaching pupils with albinism to be knowledgeable of their pupils’ situation so that they are able to reach their educational goals.

Based on the reviewed literature it is evident that, different scholars like Ndomondo (2015); Hong, zeeb and Repacholi (2006); Lund and Gaigher (2002); Mc Bride & Leppard (2002); Gaugher, Lund & Makuya(2002), McAthur (2015); Burke (2012); The National Organization for Albinism and Hypopigmentation “NOAH” (2002); Moe (2011); Allen (2010) and Uromi (2014), on their

researches conducted on the case of Albinism has spoken on the health systems, Social psychological phenomenon and in most cases those literatures have tried to explain the overall challenges facing people with Albinism as a whole. These being the case the researcher brought in the special study of the experiences of primary school pupils with albinism who apart from other common challenges facing all people with albinism they have their other academic experiences. It is also true that the scholars mentioned above did not do their research in the area of this research study that is Misungwi District found in Mwanza Region in Tanzania and the researcher finds the necessity to do so.

1.6 Methodology

The approach used in this study was qualitative. In depth inquiry of the respondents was on the study themes was conducted by the researcher on the experiences and challenges of pupils with albinism in Misungwi district, Mwanza Region, Tanzania. Qualitative techniques including face to face interviews and face to face open-ended questionnaire inquiry were conducted. Ethnographic research design was applied in this research. Albinism experiences and challenges among pupils were a sensitive matter and therefore a careful approach in data collection and management by the researchers. These included the life-threatening moments that they are going through, important in this study. Thomas (1993 as sighted in Creswell 2012), highlights, “Critical ethnographies are a type of ethnographic research in which the author is interested in advocating for the emancipation of groups marginalized in our society” (p. 467). For sampling purposes, the study used typical purposive sampling techniques because the respondents were privy to the experiences of the study population- albino pupils. Kombo & Tromp (2006) “typical case sampling: uses one or more typical cases (individuals, families/ households) to provide a local profile” (p. 83). The study was carried out in a Misungwi district primary school as a representative of Mwanza region schools. Mwanza region was selected because it is one of the five regions of Tanzania where human rights abuse among people with albinism is high.

The target population of this study was 15 participants, who were primary school pupils with albinism, their teachers, a patron and the School head. The population of the study involved one boarding primary school where albinism pupils study and live. The population selected in this study was a purposively selected because of the need to get firsthand information on the experiences and challenges of pupils with albinism and accomplish the study’s intended goals. In this study, the study sample comprised of 10 primary school pupils with albinism, 3 teachers teaching pupils with albinism, 1 patron and 1 head of school with experience of working in a school where pupils with albinism to study. A sample size of 15 participants was therefore selected with the intention of getting in-depth experiences of pupils with albinism. To analyze the qualitative data, respondents were given two different kinds of codes. For the albinism pupils who respondent to the open ended questionnaire, their code was ranging from PQRNo1- PQRNo10. Teachers, the patron and head teacher were coded TSSINo1-TSSINo4. The qualitative data was translated and interpreted. Relevant literature supporting this data was used to give further relevant theoretical meaning. Literature review and data collection process was done in the year 2016. For relevance purposes, the researchers updated the literature review for this study in the year 2021.

1.7 Study Findings

Response rate

Due to the fact that the researchers used typical purposive sampling techniques in data collection, the response rate was 100%. All the fifteen participants responded to the semi-structured interviews guide schedules and the face to face open ended questionnaire. Some documents relevant to this study were also analyzed and interpretation to the qualitative findings done accordingly. From the data collection tools, pupils responded to the questionnaire, and the rest semi-structured interviews. Document analysis included the school rules and regulation documents as well as government policies on the protection and care of children. The UN Convention of the rights of the child charter (UN-CRC) was also useful in this study.

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- **Health Challenges Facing Primary School Pupils with Albinism**

The respondents narrated some of the most challenging health problems albino children were experiencing: - poor vision, lack of balanced diet, absence of the reliable safe source of water and scarcity of protective devices to protect pupils with albinism against the scorching sun effects. Others had skin problems.

Pupils experienced many problems including vision related and poor nutrition in their school. Another challenge these pupils experienced was unreliable and unsafe water in their schools. They could get water supplied in their school two times a week. One of the albino pupil responded the following in the open ended questionnaire:-

“We have a short sightedness problem so we cannot see if we do not squeeze close to the blackboard and majority of pupils with albinism do not have spectacles]. Translation: in most cases we only eat stiff porridge and beans and in few cases we eat rice but we don't eat fruits.” (PQRNo5, 3rd February, 2016).

One of the teachers who respondent to the semi-structured interview guides narrated the following in relation to the status of children health in the school.

“Sometimes, the lotion we give to them to apply on their skin is not enough... ..we are out of stock. Sometimes, these pupils are like forced to play under the scorching sun without protection (no sun glasses, long sleeves, and hats). It is obvious; some of them have the skin problems, poor vision, among other health problems”. (TSSINo3, 5th February, 2016).

The above findings concur with empirical studies previously conducted in Tanzania, South Africa, Nigeria and Zimbabwe concluded that, people with albinism are challenged differently including being susceptible to harmful effects of ultraviolet radiation exposure which leads to decreased visual acuity and sometimes skin problems (Hong, Zeeb & Lepacholi, 2006). Again, Moe (2011) noted that, severe visual conditions may force students to drop out of school. Considering these reviews, primary school pupils with albinism need proper health care like regular checkups, skin clinics, vision aids as well as guidance on dressing. If it were not for the government policy to have albinism pupils institutionalized, they could be missing school as asserted by the TSSINo3 above. However, the suffering of the pupils was evident.

- **Social Psychological Challenges that Primary School Pupils with Albinism Face**

Worries, moods and uncertainties and deep feelings covered faces of pupils with albinism when discussing the issue of social psychological challenges. Majority of pupils with albinism seemed not to know their tomorrow due to the continued rumors, perceptions and discouragements from their surrounding world. Abandonments, being taken for granted and being forced to live in boarding school from their tender age seemed to be a very painful experience. Some of pupils with

albinism when responding to social psychological challenges could not hold their feelings which were evidenced by tears. Primary school pupils manifested that their social psychological challenges have roots from their home and communities around them; this made them lose confidence and self-esteem. Missing their parents, siblings and relatives they lived together before being sent to school was also an issue. Being forced to study in boarding school at young age as a government regulation on their safety also traumatized them. Another albinism pupil with wrote in the open ended questionnaire:

“Personally, I do not feel happy learning in boarding. I would like to interact with the society, go to school and then go back to my father’s home where I can be with my father, mother, brothers and my sisters”. (PQRNo8, 3rd February, 2016).

From the above comments from a pupil with albinism, it is calling the whole community to understand that pupils with albinism need security and love from the people around them. Security for this vulnerable group should not overtake the fundamental need of love from their own parents, friends and community as well.

The above findings concur with those of other researchers previously in related literature. Burke, Kaijage and John-langba, (2014) carried out a research through a human rights watch organization and explained:- When the killings began, some children were immediately told to stop school by their teachers and others were involved in child labour against their will. Children were given names for example “Chinese”, “Mbulimwelu” “meaning white goat”. The government directed the district and community leaders to bring in Albino Children to the established “Temporary holding shelters” – special boarding school for their protection and education. An interview with a rights watch group contacted to children, their family members, education professionals and NGO representatives in Mwanza and Simiyu regions in Tanzania found out that, “Tanzanian government policies designed to protect children with albinism incidentally had a negative impact on their rights to family life, an adequate standard of living and inclusive education. In order to protect their privacy and shield them from potential repercussions, the names of most interviewees referred to hereafter have been changed. While the Tanzanian government appears sensitive to these concerns, it should now intensify efforts to reinsert children with albinism into their communities and provide them with inclusive education, while continuing to investigate and prosecute those responsible for attacking children with albinism. By doing so, Tanzania has an opportunity to emerge as a strong African leader in ensuring the safety, inclusion and dignity of people with albinism, as outlined in the Regional Action Plan on Albinism in Africa, the first-ever continental strategy to address violations against people with albinism, adopted in 2017”.

Some pupils with albinism however admitted that even if they loved their relatives they were afraid of living in their families due to fear of their security. They felt safe at school because of the presence of two fences, guards and policemen every day. Bullying and calling names was also another social psychological issue raised by primary school pupils with albinism especially when they go for holidays. This was justified with a pupil narrating: *“Sometimes when I walk around when I am at home people stare at me, others tease me and sometimes they call me names, they say I am white and I don’t feel good; others also call me Zeruzeru, mzungu”.* (PQRNo10, 3rd February, 2016). With this statement it is evident that the communities are not well informed or educated on how bullying or name calling to marginalized groups of people like people with albinism makes them feel bad.

From this study, it was also realized that, some pupils were abandoned by their parents after they are admitted to school. This has denied them the opportunity for holidays and the school environment to them has become so boring. Their fear is that, after primary school, they will also join another boarding school – secondary school. One pupil respondent by writing the following:-

“Most of our parents after bringing us here to school they abandon us and that is a big challenge. They stigmatize us thus our school, teachers and our care takers here at school are having a big burden of giving us all our needs. We don’t know and we are not sure how long this will take. This will continue after primary school and I am sure nobody will even pay me a visit in the secondary school”. (PQRNo2, 3rd February, 2016).

Giving her own experience in regard to abandonment by relatives, another ten years old pupil with albinism wrote the following:

“I was 6 years old when I was brought here at school, from when I come here I have never been visited or even picked up during holidays. I feel very sad; I wish they could be picking me up for holidays. I wish I could see my home environment again, I miss my grandmother and father so much because my mother died. Even the clothes I am now wearing I have borrowed from my friends and only teachers who buy for me everything. Something I hate so much here is not to go home”. (PQRNo1, 3rd February, 2016).

From these findings, it can be noted that, majority of pupils with albinism are said to be abandoned in schools after being admitted or registered in the boarding schools. Pupils with albinism that are abandoned are very young – from two years to fifteen years or above. It is at this age when they really need parental guidance in all development aspects including emotional, physical, social, sexual, intellectual, cultural and spiritual growth. This may lead to growth and development challenges among children in the future and eventually affect their social, emotional and academic lives.

Another encountered psychological challenge revealed in this study is lack of freedom among some primary school pupils with albinism. According to some of them they feel like they are not free even in their school environment because they are always within the school fence and they are not allowed to go out at all except during their holidays. Explaining this in writings one of the student with albinism wrote:-

“Sometimes I feel like a prisoner because I do not have a chance to see the world because we are always within the fence guarded with police men just like in the prison” (PQRNo6, 3rd February, 2016).

Teachers teaching primary school pupils with albinism likewise mentioned of the challenge of some parents abandoning their children as soon as they drop them at school. However, teachers teaching special needs education are also psychologically affected because they think the Government does not recognize their working conditions despite working in very hard situations. One of the teachers narrated the following:-

“In most cases we use our own extra time but we are not given motivation or even any allowance, so it reaches the time we leave it in the hands of God and decide to volunteer because we have no way out”. (TSSINo4, 11th February, 2016)

The above statement given by this teacher shows that, teachers in special needs schools are not working whole heartedly or with passion but rather work in frustration and stress. This simply

means if they teach without encouragement, then pupils are not likely to get the intended quality of education or care that is supposed to be given by their teachers.

Previous literature confirms the above findings to be true. Under the Same Sun (2016), reported on a baby boy's body being exhumed from the grave in May, 2016. These threatening activities led to the government and Non-Governmental Organizations to create centers for securing people with albinism who can no longer live freely like any other human beings due to fear for the continued hunts and killings. It is in these centers where a number of albinism children suffer isolation and loneliness. Further to these assertions by previous researchers, Tanner (2010) noted that, within only one month of June, 2009 in Sukuma Land located in North West Tanzania 48 people with albinism were killed in search for their body parts to be used in superstition activities. Such experiences have left albino children live in fear for their lives.

- ***The Academic Challenges Facing Primary School Pupils with Albinism***

In the endeavor to find out the kind of challenges pupils with albinism face, respondents in the school that participated in the study were invited to share their views on what from their personal experience. Primary school pupils with albinism gave their contributions through the open ended face to face questionnaires. Most of them said the academic challenges included:- low vision, and because of that they needed spectacles or magnifiers (lenses) which can help them see clearly on the black board and books. Some of pupils with albinism said even if they have desks to sit on because of the short sidedness challenge, they were forced to sit down closer to the blackboard to be able to see clearly. The following is a written narration by one of the pupils:

“Sometimes, I do ask my classmate to help me read from the black board ...she can or other times refuse, therefore I need to go very close to the blackboard and then come back repeatedly to write because, for example for me to see properly on the black board I need to be only one meter from the black board but sometimes I need help from someone to read for me”. (PQRNo6, 7th February, 2016).

The other identified problem is shortage of desks for pupils to sit on, therefore some of pupils including pupils with albinism are forced to sit down when learning.

Like primary school pupils with albinism, teachers also pointed out the same challenges of poor vision and shortage of desks among their pupils with albinism. Teachers unlike pupils pointed out other critical challenges, including lack of proper teaching and learning materials like special books or exercise books with big font size in order to allow pupils with albinism to study without struggles. Overcrowding of classes was also noted, in that a class that is supposed to have only 45 pupils accommodates 100 to 180 pupils. Some teachers with special need education to handle both the special needs pupils who are albinos, deaf, deaf mutes and blind. However teachers also spoke of the challenge of not having the projectors which would help teachers to easily project their notes with large prints which would enable every pupils to sit anywhere and at the same time be able to catch-up with everything than the use of blackboard, the absence of Braille machines, classroom modifications, teachers teaching special education are not motivated or given extra duties allowances, they are just treated like any other teacher who teaches pupils without special needs. One teacher teaching the upper primary school pupils responded to the semi-structured interview guide:

“For sure, we do not get any motivation as those who teach pupils with special needs like pupils with albinism, and I think that is not proper at all because teaching these pupils

needs special teaching techniques and in most cases we even use our own extra time, it reaches a time when we decide to leave everything under God's hands. I think those teaching pupils with special needs should be given some consideration. At least we should be given the teaching allowances or extra duty allowance or if possible our salaries should be increased" (TSSINo2, 11th February, 2016).

The above findings concur with those of a number of previous researchers including Ndomondo's and Nicopolis ltd. From their research, it was noted that; stigma and discrimination encountered by this group of people threaten their academic performance in many ways. Teachers, managers, educational supervisors and community members are still not knowledgeable of the needs and wants of pupils with albinism (Ndomondo, 2015). The Tanzanian Albinism Society reports as sighted by Nicopolis Ltd (2016) that: "A very high number of children with albinism are dropping out from schools because of the intense discrimination that they face within the 'inclusive education' systems. A very large proportion of these children are suffering from rejection, anxiety, fear, post traumatic disorders and sexual abuse due to superstitious beliefs in Tanzania that if one sleeps with a person with albinism, one can get cured from HIV." Lack of books with large prints is also a challenge to most schools which have pupils with albinism (Ndomondo, 2014).

- ***Measures that Can Be Taken to Improve the Learning Environment for Primary School Pupils with Albinism***

After data collection and analysis, measures that could improve the learning environment for the primary school pupils were proposed. These measures were classified as either academic, health or social psychological. Supportive and friendly environment is important as a learning environment for primary school pupils with albinism.

- ***Academic Measures for Improving the Learning Environment for Primary Pupils with Albinism***

Views and solutions to some challenging issues on academics that primary school pupils with albinism face were aired out by the respondents in this study. The issue of modifying infrastructures to meet the academic needs of pupils with albinism emerged as critical issue that majority were concerned with. Participants evidenced that the infrastructures that were still used were old and not constructed according to the physical disabilities needs of pupils with albinism. Nevertheless, majority of participants were concerned of the addition of Braille machines to fit the whole population of primary school pupils with albinism. Text books with bigger font size was another suggestion that majority of participants recommended for primary school pupils to have the opportunity to study from books like other pupils without visual impairments.

The use of technological devices like computers and projectors were among suggestions by majority of participants in order to improve the learning environment for primary school pupils with albinism. The use of projectors was viewed as a solution to majority of pupils with albinism who could not read properly from the black board. However, participants spoke of the government to see the necessity to train more teachers in special needs education. It was however observed that, teachers who were knowledgeable of the needs and requirements of primary school pupils with albinism were still few and lacking the professional skills.

Reacting to the issue of infrastructure some participants suggested that the school educational infrastructures should be improved. More classes should be built so that pupils are not overcrowded in classes. Suggestions like classes and buildings should be built with the consideration of pupils with special needs like pupils with albinism were given. Cementing on this one albinism teacher explained:

“Infrastructure should be improved because for example we only have one class connected to the electricity system. New buildings under construction should be supportive to the needs of our special students. Since 2007, we have been receiving new students and more with special needs and not much improvements on the infrastructure for their learning and development. The buildings are outdated and lack the necessary facility for the albinism children especially” (TSSINo3, 11th February, 2016)

- *Social Psychological Measures That Can Be Taken to Improve the Learning Environment for Primary School Pupils with Albinism*

Participants revealed the need to address and educate communities on the issues facing pupils with albinism. Majority of primary school pupils with albinism who participated in this study suggested mass education of the Tanzanian population to be acquainted with information on the special needs of albinism.

Majority of pupils with albinism requested for the government’s intervention in solving the challenge of some parents abandoning them in boarding schools after they are admitted. The primary school teachers and the albinism pupils condemned the inhuman treatment by parents who never showed up to their children nor visited for basic necessities of life support. Inclusive education was important in dealing with misconceptions and building confidence among primary school pupils with albinism. Majority of primary school pupils with albinism said they felt better to study with other pupils without albinism because they felt equal and could help each other. Through inclusion, primary school pupils felt like they could also do activities that other children without albinism could do, this helped to build their courage and confidence.

- *Health Measures that can improve the Learning Environment for Primary School Pupils with Albinism*

Different opinions on helping to solve the challenges that pupils with albinism face were given by the respondents. Majority of participants suggested on the medical checkups on pupils with albinism. They also sought the support of the government and other stakeholders to make sure that crucial services like water, balanced diet and proper health devices to every student with albinism should be availed. Safe water and regular skin care for the albino pupils in school was also another support pointed out by the respondents. Community awareness on the rights of the pupils living with albinism was an idea to be advocated for by all. Among other issue of interest was their security and awareness creation on the myths surrounding their body parts in which the superstition demands were misleading among the members of the public.

- **Conclusion**

After carrying out this research on the challenges experienced by pupils with albinism in Misungwi district schools, we conclude that, this population experiences many challenges ranging from physical health, psychosocial and academic challenges. It is also fair to conclude that, the government of Tanzania has taken important steps to protect people living with albinism; however,

awareness and sensitization on human rights and the rule of law in protecting and caring for this vulnerable population has not yet been realized. Furthermore, we also conclude by saying that, stereotypes and labelling among the target group increases stigma and discrimination. Name calling was very common even among very close members of the family and this is associated with ignorance on the effect this can cause among children living with albinism. Additionally, we conclude by saying that it is in our view that, there exists a severe lack of well-defined plans or even dependable infrastructure for holistic health programs among children with albinism in Tanzanian schools, particularly in Misungwi.

Recommendations

To the Government of Tanzania

- i. Increase public sensitization and awareness efforts aimed at dispelling deadly and discriminatory myths about albinism, notably through workshops and public service announcements on radio and television, particularly in rural and isolated communities.
- ii. Ensure that all those working in primary school system are trained on special service delivery for children living with albinism.
- iii. To avail resources for schools to meet the needs of children living with albinism (Improvement of infrastructure, reading materials and aids, special reading materials, among others)
- iv. Together with responsible state-holders, initiate and implement humane mechanisms for the safety, care, protection as well as the re-integration of children with albinism back to their families. In connection to this, institute punitive measures to deter crimes and threats against people with albinism.

Primary Schools community

- i. Collaborate with pupils, families, relatives and the community at large in understanding and meeting the holistic needs of children with albinism.
- ii. Initiate counseling services for the affected pupils in their schools and possibly professionals like psychologists or social workers
- iii. Be the custodians of the government policy and laws in enhancing the human rights for children living with albinism.

Family members, the community and Society at large

- i. Understand and do their responsibilities especially to their children with albinism, including basic necessities of life, emotional needs, as well as a place where they feel they belong – a home.
- ii. Help in building the self-esteem of their children by encouraging them to cultivate their passion and talents
- iii. Support the government efforts in ensuring safety, care, protection, and receiving re-integrated children back to their families.

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