COMMUNITY PERCEPTIONS TOWARDS PERSONS WITH ALBINISM

A QUALITATIVE STUDY ON SELECTED REFUGEE SETTLEMENTS IN UGANDA, 2021.
ABSTRACT

Background: Persons with albinism are faced with challenges related to the color of their skin, hair and eyes which is caused by lack of the melanin pigment in their skin. These challenges have not been well studied and documented because of factors that include but are not limited to; societal fears and myths, poor legislation and ignorance about albinism.

Aim of the study: The study sought to determine the perceptions towards persons with albinism among selected refugee settlements in order to inform decision making and policy on programming for this vulnerable population.

Methods: This study was conducted in 2021 in three refugee settlements. We employed a qualitative descriptive study design with purposive sampling of the refugee settlements and study participants. A semi structured interview guide was used to collect data from the focus group discussions and from the key informants. Six (6) Focus group discussions with women and men groups and three (3) key informant interviews with a community-based protection officer, community services assistant and the settlement commandant were conducted. Thematic data analysis was used to determine refugee community perceptions towards albinism.

Results: Participants of the study highlighted four major themes. These are stigma, difficult livelihood, Fear and inherent challenges.

Conclusion: The perceptions of communities housing persons with albinism in refugee settlements are characterized by stigma and fear of being sacrificed by community members, scorching sunshine that pre-disposes persons with albinism to skin problems and a lower level of livelihood compared to the rest of the communities in which they live.

Keywords: Albinism, refugees, perceptions
FOREWORD

In the world today, anyone can become a refugee at any time. According to the United Nations High Commission for Refugees (UNHCR), “Refugees are people who have fled war, violence, conflict or persecution and have crossed an international border to find safety in another country.” Uganda has the third largest refugee population in the world (UNHCR 2021). Majority of refugees in Uganda are from South Sudan followed by Democratic Republic of Congo, Burundi, Somalia, Rwanda, Eritrea and Ethiopia.

Persons with albinism, like many refugees fled to Uganda in search for a safe haven however their hopes have been dashed. Albinism has its inherent challenges among which stigma and discrimination rank the highest. This is exuberated by the refugee status which is a mixed community with different beliefs and backgrounds.

Albinism Umbrella purposed to interrogate this predicament of refugees as a special category in order to amplify their voices and call upon relevant stakeholders to this double marginalization of the community. In the three settlements that were visited, stigma, fear for their lives and poverty ranked the big setbacks to living meaningful lives.

“The people we live with are not happy with us and they say we are money, we are medicine for demons and good for witchcraft” cries one respondent.

A mother lamented that her child suffers rejection right from birth at the hospital until adulthood. This is a common phenomenon for refugees with albinism as others do not consider them as fully human. The low literacy rates and ignorance breed dangerous superstitions that put the lives of persons with albinism in danger. The perceptions of communities housing persons with albinism in refugee settlements are characterized by stigma, fear of being sacrificed by community members, the scorching sunshine that pre-disposes persons with albinism to skin problems and a lower level of livelihood compared to the rest of the communities in which they live. Sunscreen are so limited in supply and irregular yet without this protection, skin cancer is glaring to worsen the status.

Why shouldn’t we share this beautiful planet with others who are different? As the world enjoys the benefits of globalization, we need to remember that inclusion is a choice while diversity is a fact of life.

Olive Namutebi
Executive Director
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According to the UNHCR statistics, there were about 27 million refugees worldwide by mid-2021 and Uganda is the third largest host of these refugees, (UNHCR 2021). Refugees usually migrate to neighboring countries when either faced with life threatening situations or bare minimum standards that support comfortable living cannot be met in their own countries of origin (Frontières 1997). Majority of refugees in Uganda are from South Sudan followed by Democratic Republic of Congo, Burundi, Somalia, Rwanda, Eritrea and Ethiopia. Refugees with albinism face a number of challenges in addition to those associated with their refugee status. In Africa, albinism is associated with witchcraft, sacrifices and various myths and beliefs which are a threat to this vulnerable population. There is a belief in some African communities that body parts of persons with albinism bring luck and prosperity (Chikwela 2015). In Tanzania for example, persons with albinism are hunted, killed and body parts used for witchcraft and sacrifice. It was until recently that the government banned the killing of persons with albinism and put deterrent statutory punishments for whoever is caught getting involved in the act, (Brocco 2016). While such practices happen in communities where persons with albinism have several options, challenges faced by persons with albinism in refugee settlements may even prove to be more dangerous given the different behavior of people from different countries , (Nkrumah 2018).

Different studies report that such behavior has manifested as ridicule and discrimination in some refugee communities and yet little or nothing is done even though cases are reported to authorities with ability to administer appropriate punishment (Chikwela 2015). There is therefore a need to understand refugee community perceptions towards persons with albinism in refugee settlements in Uganda- a gap this study seeks to fill.

1.1 BACKGROUND

Albinism is a genetic disorder that presents with lack of melanin in the hair, eyes and skin pigments.,(Cruz-Inigo, Ladizinski et al. 2011). It is a condition characterized by photophobia, decreased visual acuity, extreme sun sensitivity and skin cancer, (Hong, Zeeb et al. 2006).

In Uganda, persons with albinism have been categorized as persons with disability (PWD), (UBOS 2018) after revising the earlier persons with disability act of 2006 which did not recognize this population as persons with disability. However, persons with albinism have
been found to experience at least two or three of the disability domains which include seeing, hearing, walking, communication, self-care and remembering. As a result of revising the act, persons with albinism were recognized as persons with disability and their programming is done through existing frameworks. In spite of these changes in the act, it has been challenging to formulate frameworks through which tailored interventions and programs are made for persons with albinism. This situation is further worsened by the limited robust studies on perceptions of refugees towards persons with albinism in refugee settlements in Uganda to inform decision making and programming. Refugees have varying degrees of vulnerability and those with albinism need more security and protection with tailored interventions and support to deal with their unique health and social challenges (Abbas, Aloudat et al. 2018).
2.0 DISCRIMINATION:

A study in a refugee camp in South Africa revealed that women were discriminated against in public health care facilities. They experienced negative attitudes from nurses in particular who in some instances neglected them and denied them access to health care services (Munyaneza and Mhlongo 2019). They were shouted at and fingers pointed at them in addition to the long waiting time they had to endure and yet didn’t get the services they required. Discrimination was also cited among refugees resettled in the USA and it was mainly towards refugees from African countries, (Hadley and Patil 2009). This vice affects livelihoods and particularly is a barrier to accessing health services. Discrimination was also one of the barriers faced by refugees from Somalia in Eastleigh Kenya as the could not access mental health services at the health facilities, (Mutiso, Warsame et al. 2019). In a study to describe voices of women refugees on reproductive health services in public health institutions in Durban KwaZulu-Natal, discrimination was one of the main themes under negative experiences and challenges to accessing services, (Munyaneza and Mhlongo 2019). Studies have also shown that discrimination has negative effects on the mental health of refugees, (Kirmayer, Narasiah et al. 2011). Persons with albinism are discriminated against due to their physical appearance and having a refugee status only amplifies the situation. This population continues to be harassed and killed and yet not much is being done to protect them from their persecutors, (Nkrumah 2018). Refugees with albinisms face many more challenges including death through witchcraft as sacrifices, (ANSA 2020). The health and social issues affecting persons with albinism in Africa have not been well studied and documented, (Hong, Zeeb et al. 2006). The lack of robust studies and documentation about issues affecting refugee communities especially of health related aspects is a threat to both the refugees and the host country since the two populations interact and are integrated in the long run, (Munyaneza and Mhlongo 2019).

2.1 ILL TREATMENT:

As a result of the harmful representations of persons with albinism in African traditions and cultures over many years, this population has continued to be vulnerable and threatened by injustices, killings and all sorts of ill treatment, (Imafidon 2018). The different beliefs and customs account for the ill treatment towards persons with albinism in many societies in
Africa. In Tanzania, children born with albinism were considered abnormal and their mothers were required to kill them, (Masanja, Imori et al. 2020). This population has been hunted for sacrifices, witchcraft and rituals as they are believed to bring good luck and prosperity.

2.2 SOCIAL STIGMA:

Persons with albinism face social stigma because of the way they are perceived by different communities. They are looked at as different people because of their skin, hair and eye color. This population is not only physically different but even their way of life in terms of what affects their health, the suitable environment they need, and so this presents a platform for social stigma, (Imafidon 2017).

2.3 KNOWLEDGE ABOUT ALBINISM:

Persons with albinism do not know the cause of their condition and this ignorance makes them even more vulnerable (Udongo Betty Pecutho 2018). Low literacy rates and ignorance breed dangerous superstitions that put the lives of people with albinism in danger. This coupled with the challenges of being a refugee makes it very difficult for this vulnerable population to live in harmony and thrive in their communities. A qualitative study done in Tanzania revealed that despite the attempt to sensitize the population about albinism, majority of the people in the community had scanty knowledge about albinism.
CHAPTER THREE

PROBLEM STATEMENT

PROBLEM STATEMENT:
Refugees with albinism continue to face challenges in addition to those associated with their refugee status and yet not much has been done to study these challenges and document them for decision making and tailored programming.

MAGNITUDE OF THE PROBLEM:
While different community studies show varying perceptions of people with albinism, there is a scarcity of studies elucidating perceptions of refugees towards persons with albinism in refugee settlements in Uganda.

WHAT HAS BEEN DONE
There are global and national laws protecting persons with albinism from the threat of harm and or discrimination. In an effort to mitigate the socio-economic divide, the government initiated a startup grant for persons with disabilities who include persons with albinism. In addition, there was an intervention in 2018 aimed at profiling persons with albinism in selected districts in Eastern Uganda.

WHAT WE DID
We interviewed refugee women and men with albinism in three refugee settlements to determine perceptions of refugee communities towards persons with albinism.

JUSTIFICATION OF THE STUDY:
This study will aid AU in designing data-based strategies that will improve the holistic well-being of persons with albinism. The results from the study will inform planning and programming for refugees with albinism with tailored interventions suitable for their condition. The results of this study will also be used by civil society organizations and other implementing partners to rebuild family and community structure support. This will be done through local capacity building and community empowerment efforts that reduce the discrimination of persons with albinism in refugee communities.
The study findings will also help in designing tailored interventions for refugees with albinism to reduce stigma and discrimination and ill treatment in the communities, health facilities and schools.
OBJECTIVE:
The overall objective of this study was to determine community perceptions towards persons with albinism in selected refugee settlements in Uganda.
CHAPTER FIVE:
MATERIALS AND METHODS

5.1 STUDIO AREAS AND SETTING

The study was conducted in three selected refugee settlements in Western Uganda. These are Nakivale Refugee settlement (Isingiro district), Rwamwanja refugee settlement (Kamwenge district) and Kyaka refugee settlements (Kyegegwa district) respectively.

5.2 STUDY DESIGN

The study employed a descriptive qualitative study design using Key Informant Interviews (KII) and Focus Group Discussions (FGDs). Scholars have recommended KII and FGD as adequate methods of eliciting information in qualitative descriptive studies (Sandelowski 2001, Neergaard, Olesen et al. 2009). In addition, the investigators of this study wanted a comprehensive understanding of refugee community perceptions towards persons with albinism in the three selected refugee settlements. In order to achieve this, a qualitative inquiry methodological approach was used (Sandelowski 2000). Sandelowski and colleagues also advise that a qualitative descriptive study be employed when researchers want to stay closer to the data and surface of the gathered information, words, and events (Sandelowski 2000, Sandelowski 2010).

5.3 STUDY PARTICIPANTS

Key informant interviews were done with the community-based protection officer, community services assistant and the settlement commandant. Focus group discussions were held with persons with albinism within the settlements that were visited. Unique identifiers that may have been used to link the collected data to the respondent in this study were removed in line with upholding confidentiality of participants involved in qualitative studies (Kaiser 2009).
5.4 SAMPLING PROCEDURE

Participants involved in this study were purposively sampled because they were knowledgeable about community perceptions towards persons with albinism while the men and women with albinism were chosen because they had a lived experience (Palinkas, Horwitz et al. 2015). The sampling was based on: 1) being in a position of authority in the selected refugee settlement; and 2) being a person with albinism in the settlement.

5.5 DATA COLLECTION

This section details how data was collected from the study participants within the three refugee settlements that were visited. The section shows how data was collected from people with influence within the refugee settlement also known as Key informants as well as persons with albinism who were involved in the focus group discussions.

KEY INFORMANT INTERVIEWS

Three people believed to be more knowledgeable than other people in the refugee settlement were purposively selected for key informant interviews (KIIs). The KIIs were conducted from the different offices of the respondents in the different settlements. During interviews, plain questions were followed by probing questions where necessary to get a deeper understanding of community perceptions towards persons with albinism. This was done until saturation was attained. That is to say, until no new information arose to warrant additional interviews (Guest, Namey et al. 2020). The interview guide explored what the communities knew and felt about persons with albinism and vice versa, whether the communities felt there was any difference between them and persons with albinism, the extent to which communities had been helpful to persons with albinism and how best the later could be helped.

By the third KII, there were no new issues arising from the interviews and hence we believed that saturation had been achieved. The team leads in the three refugee settlements informed the key informants about the interviews both verbally and in writing.

FOCUS GROUP DISCUSSIONS

In each of the refugee settlements, FGDs were conducted with persons with albinism. Each FGD comprised of eight to ten participants (Carlsen and Glenton 2011). In total, 50 persons with albinism were purposively selected for focus group discussions (FGDs) in the three selected refugee settlements. Of the five FGDs conducted in the three refugee settlements, two were with men. All the FGDs were conducted from base camp which is the nearest ward to the settlement commandant. This was done to protect and uphold the rights of refugees against any form of harm and or harassment from the study team. The team leaders informed the
persons with albinism about the interviews through the research assistants assigned to the three refugee settlements.

Photo 1: Male focus group discussion in Nakivale refugee settlement

5.6 TRAINING AND QUALITY CONTROL

Two research assistants (RAs) with advanced degrees in health services research and refugee and migration studies were recruited and given refresher training on qualitative data collection methods and tools. In addition, two note takers were recruited and paired with each of the research assistants. On average, each KII took 45 minutes to complete while each FGD took an average of 60 minutes. While the interview guide was in English, the research assistants converted it to Swahili, Kirundi, Kinyarwanda and Runyankore /Rukiga during the interview sessions. A drink and something to eat was provided to all participants since all interviews started mid-morning on the data collection days. This time was agreed upon with the settlement commanders since mobilization for participants who were living in faraway wards had to be done. All discussions and interviews were audio recorded.
5.7 DATA MANAGEMENT AND ANALYSIS

The transcription of all the audio recorded interviews was done for one week after which transcripts were uploaded into Atlas ti version 7- qualitative data management software (ATLAS.ti GmbH, Berlin). The investigators of the study took an interpretivist ontological and constructivist epistemological position because they believed that societal perceptions towards persons with albinism were socially constructed (Hudson and Ozanne 1988, Colorafi and Evans 2016). The transcribed data was analyzed with the aim of understanding the contextual perceptions of communities towards refugees who are persons with albinism in the selected refugee settlements in Uganda in order to recommend improvements where the perceptions fall short of what is acceptable. Texts from uploaded KIIIs and FGDs transcripts were first coded before being selectively divided into meaning units and subsequently condensed meaning units (Graneheim and Lundman 2004). The coding and labeling were done by the two team leaders of the study. Each leader coded one KII and one FGD transcript independently. The generated codes were compared for similarities and differences before being merged. The agreed upon codes together with other emerging codes were then used to code the rest of the transcripts. We believe that this greatly increased the trustworthiness of the results (Johnson, Adkins et al. 2020, Nyirenda, Kumar et al. 2020). Different scholars also argue that using different people in triangulating findings has the potential of improving the interpretive rigor of a study such as this one (Maher, Hadfield et al. 2018). The various codes were then merged to form sub-themes after careful comparison. The sub-themes were further condensed into higher order themes.
CHAPTER SIX

RESULTS

This study set out to determine community perceptions towards persons with albinism in three selected refugee settlements in Uganda. Four major themes emerged from the study. These were: stigma, difficult livelihood, Fear and inherent challenges.

STIGMA

Stigma stood out as one of the most talked about themes in the refugee settlements that were visited. Majority of the respondents said that the main challenge they faced on a day-to-day basis was the lack of respect from society. This lack of respect has resulted in a lack of inner peace wherever persons with albinism go because the community does not consider them as human beings. Relatedly, majority of the female respondents said that persons with albinism were stigmatized right from the time they were born until they became adults. To that effect, most mothers in the focus group discussions intimated that right from the time they gave birth to an albino child throughout the entire hospital stay, they felt scared. The mothers also said that many a time, this scary feeling continues throughout adulthood because they have had to closely follow their children everywhere they go since refugee societies discriminate persons with albinism which makes them lose their peace.

“Another challenge mothers face, is when you give birth to a child like this (albino), to be truthful you feel a little scared. We keep saying this is my child, I gave birth to them. But to live with them is hard and necessitates following the child everywhere they go which makes us loose our peace” (Participant 3, FGD, Females, Rwamwanja)

Photo 2: Mother with a baby with albinism
Even among the male focus groups, stigma was a very highly talked about subject. The male refugees with albinism intimated that the main reason they left their countries of origin was because they wanted a safe haven and a place with assured security and assured means of livelihood. However, most of their hopes have been dashed.

“I think nothing of that sort has happened. We don’t get any help apart from UNHCR. They give us 18,000 shillings per month. Apart from that, no one has made an effort to help us.” (Participant 8, Male FGD, Rwamwanja)

The key informants on the other hand said that persons with albinism were neglected but not segregated contrary to what many people insinuated. They said this stemmed from the fact that refugees in the settlements had their own pre-conceived beliefs which put persons with albinism at a higher risk of being neglected compared to other community members. The key informants said that because of these pre-conceived beliefs, even parents of persons with albinism felt uncomfortable supporting their own children to a large extent.

“You know, refugee communities have traditional beliefs that are tagged to persons with albinism which puts them at a high risk of being neglected, segregated and not being supported. You might find that even the parents of persons with albinism feel uncomfortable supporting them. Even when albino children are at school, when they are walking by, you see many children following them and referring to them as muzungu [a term meaning white person].” (KII, Kyaka II refugee settlement)

FEAR

Related to stigma was the fact that many persons with albinism and caregivers of persons with albinism lived in fear for their lives and the lives of their children respectively. Majority of the women and the men in the focus group discussions that were held said that refugee communities constantly remind them that persons with albinism are hunted for business purposes. It is believed that the body parts of persons with albinism are associated with winning and getting rich.
“They hunt for albinos because they have turned us into a business. They say if you get the bones of an albino, you will win, if you get their head even better. Same applies to the hair and nails. We do not know what to do.” (Participant 6, Female FGD, Nakivale)

“Albinos are disrespected not only in Uganda but the whole of Africa. Also, persons with albinism are hunted because of their body parts. When companies want to grow, they hunt us for our body parts. We have no peace in the whole of Africa. In Uganda and Congo, an albino cannot walk for one and a half meters without being laughed at or ridiculed. They are at a constant risk of being killed by a black person.” (Participant 1, Male FGD, Rwamwanja)

The key informants also reiterated that persons with albinism lived in constant fear for their lives and as such, many provisions aimed at securing their lives are now in place. The key informants intimated that refugee communities had many myths associated with persons with albinism which resulted in all settlements housing persons with albinism to make some provisions. Such provisions include but are not limited to housing refugees with albinism nearest to the settlement commandants.

“……..there is a myth that when you sleep with female persons with albinism you get a blessing. Also, if you kill and remove private parts of a persons with albinism, you will get rich. So as a result of this, they [persons with albinism] were being disturbed in the settlement. So, OPM decided that refugees with albinism should be brought closer to the base camp not because of segregation but because of those incidences they were facing from within the community.” (KII, Rwamwanja refugee settlement)

INHERENT CHALLENGES

Another theme that emerged from refugee persons with albinism was the fact that they were not like other people within the community in terms of color of skin, hair and eyes. This was cited as the root cause of stigma and fear that they experienced. These inherent challenges were mentioned across all the focus group discussions conducted with participants in the refugee settlements.

“The first challenge we face is from the sun. When we spend the day under the sun, our skins change. They become red and itchy, and if you scratch yourself, it becomes a wound. That is the first problem. The second problem is because of our skin which is full of wounds,
As far as the males were concerned, the inherent challenges particularly affected their children especially when it came to school. They lamented that while at school, their children were laughed at because of their different skin color. Most men said that the situation at school was bad for albino children because not many black children wanted to seat next to albino children. As such, most albino children were not going to school.

“It is the same situation with schools, there is no albino child that goes to school. Even those who go are discriminated against because the other children say they cannot sit next to namagoye/kasa (meaning albino). They fear you. All students keep staring at the pupils with albinism. Thus, they are not comfortable at school. So, we tend to ask ourselves whether we are human beings or not?” (Participant 8, Male FGD, Rwamwanja)

On the contrary, the key informants wondered why persons with albinism were constantly being looked at badly. This is because to them, persons with albinism are the same as people in the community save for the fact that persons with albinism had different skins, eyes and hair.
“I don’t know whether it is impairment or a disability but to me they [persons with albinism] should be treated equally like any other human being because they possess the same blood as these other people. The mere fact that persons with albinism are born with a disability or impairment shouldn’t be the basis for them to be isolated and their rights to be neglected and or violated.” (KII, Kyaka II refugee settlement)

DIFFICULT LIVELIHOOD

From the interviews, it was noted that participants decried the situation in which they were living mostly because of the color of their skins. Most persons with albinism said they were unable to get involved in meaningful businesses because most businesses entailed being out in the sun for long hours.

“The people we live with are not happy with us and they say we are money we are medicine for demons and good for witchcraft. The body of the albinos are said to be used to remove demons in people so we are fearful. Even when you think of making a business of banana leaves and no one buys them.” (Participant 4, Female FGD, Nakivale Refugee settlement)

The key informants said that all refugee settlements with refugees with albinism have a budget for procuring items such as hats, glasses, sunscreen to mention but a few.

These items are procured and distributed with an intention of reducing exposure of sun rays onto the skins of persons with albinism. It is envisaged that by shielding sun rays from reaching their skins, persons with albinism are able to stay out for longer hours and hence improve their livelihoods by doing meaningful work. However, inadequate funds are a constant challenge.

We always procure for them [persons with albinism] hats, glasses and sunscreen to cater for their daily life. We also procure those plastic shoes but now due to a limited budget, they have spent three months without getting these items. The money which was initially allocated to cater for the needs of persons with albinism for a year was used within six months meaning that for the next six months, they do not have money. (KII, Nakivale refugee settlement)
CHAPTER SEVEN

DISCUSSION

This study aimed to determine refugee community perceptions towards persons with albinism in selected refugee settlements in Uganda. All in all, four major themes emerged from the study. These were; stigma, fear, inherent challenges and difficult livelihood.

The findings of the study show that persons with albinism in refugee settlements face unique challenges all emanating from the difference in their skin color, hair and appearance of their eyes. The findings are expected to shape the refugee policy in Uganda and the rest of the world where persons with disability in general and persons with albinism in particular are concerned.

Results from this study revealed that refugees with albinism are stigmatized by the communities in which they live. These results are similar to those from a study done in Uganda in eight districts of the Busoga region which highlighted the discrimination and stigma faced by persons with albinism (Bradbury-Jones, Ogik et al. 2018). While the results are the same, differences abound in the study setting where the two studies were done. Our study was done in refugee settlements. Refugee settlements present peculiar challenges to incoming refugees from different countries (Bempong, Sheath et al. 2019) and thus, being a refugee and a person with albinism is a two edged challenge that needs additional attention.

Study results also showed that refugees with albinism and the key informants talked a lot about the fear that refugees with albinism face. Fear among refugees with albinism has been reported by scholars elsewhere (Dehm and Millbank 2018). While in our study we found that refugees with albinism feared community members, in the study by Dehm and colleagues, it is the community which feared persons with albinism because they felt that they practiced witchcraft which was not good for the community. It is therefore important that such myths and superstitions embedded within communities are dealt with by UN and government agencies because they could spark an unwanted backlash for innocent persons with albinism.

Evidence from this study showed that both Key informants and focus group participants acknowledged that most challenges faced by refugees with albinism stemmed from the difference in color of their skin, eyes and hair from the rest of the community members. These results are in agreement with results of studies done in Busoga, Uganda where mothers were shocked and first rejected babies with albinism at birth (Taylor, Bradbury-Jones et al. 2021). In Malawi, similar challenges are faced by persons with albinism because of community misconceptions, myths and beliefs (Tambala-Kaliati, Adomako et al. 2021). Again, this goes to show that while
the study of Busoga and Malawi were done where persons with albinism have an opportunity to move to communities where they are better appreciated, our study which was done in refugee settings explores perceptions among communities where refugees with albinism more or else have their fate sealed. This is because many of them may not be able to move to new areas because of the uncertain reception they will receive even if the statutory laws guarantee free movement of refugees.

In addition, refugees with albinism face peculiar challenges when it comes to improving their livelihoods. This is because a lot of trade in the refugee settings involves staying out in the sunshine for prolonged periods of time and yet the skins of refugees with albinism lack melanin- a skin pigment that protects the body against harmful ultraviolet rays from the sun (Brenner and Hearing 2008).

The major strength of our study is that we collected community perceptions from the people in charge of refugee settlements who are very knowledgeable about the situation of the refugees with albinism within the community. We also collected information from the refugees with albinism which helped us to triangulate the results. Future studies among refugees with albinism are required to understand contextual drivers of these perceptions in the communities where refugees with albinism live. However, such studies may only be possible when legal processes and frameworks are enforced to stop the immediate discrimination of refugees with albinism. Otherwise, soon or later, this discrimination will become engraved in the minds of children preventing the free provision of information that may be helpful in changing the status quo.
CHAPTER EIGHT

CONCLUSION AND RECOMMENDATIONS

8.0 CONCLUSION

This study showed that the perceptions of communities housing persons with albinism in refugee settlements are characterized by stigma and fear of being sacrificed by community members, scorching sunshine that pre-disposes persons with albinism to skin problems and a lower level of livelihood compared to the rest of the communities in which they live.

8.1 RECOMMENDATIONS

The recommendations below are suggestions made by the persons with albinism in the selected refugee settlements that were visited.

1. Persons with albinism should be given third country resettlement swiftly since they are hunted for ritual sacrifice.

2. Health workers should have special consideration for persons with albinism and attend to them first to avoid the harmful effects of direct sunrays.

3. The OPM should prioritize provision of protective gears such as sunscreens, visual aids and wide brimmed caps to refugees with albinism. It is envisaged these will protect them against the harmful ultraviolet rays that cause skin damages and cancer.

4. There is need to train teachers to accommodate the learning needs of children with albinism preferably through the teacher training colleges.

5. There is also need to introduce large print fonts for learners with albinism to support their learning journey.

6. Persons with albinism who are scattered within the settlement should be brought to live in the same resettlement homes to enhance their safety and service provision.

7. Advocate for the advantages of integrating the refugee population into host communities.
8. There is need for continuous awareness raising about the specific protection needs and rights of refugees with albinism while providing access to migration frameworks.

9. Organisations like Tutapona, Red Cross, NUDIPU, ALIGHT, Save the Children among others should extend reintegration projects such as microfinance schemes, vocational trainings and livelihood programs to enhance the income levels for refugees with albinism.

10. There is need for deliberate community awareness raising to change community attitude and perception about albinism.

11. There is urgent need to sensitize refugee settlements within which persons with albinism live. The sensitization should aim at spelling out the causes of albinism, causes of skin cancer among persons with albinism and how to prevent skin cancer among persons with albinism.

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