Albinism, Witchcraft, and Superstition in East Africa: Exploration of Bio-cultural Exclusion and Livelihood Vulnerability

Benson A. Mulemi
[Principal Investigator]

Urbanus M. Ndolo
[Co-investigator]

Faculty of Arts and Social Sciences
Department of Social Sciences

Research Report Submitted to the Department of Research

The Catholic University of Eastern Africa
P.O. Box 62157 – 00200, **Nairobi**
April 16, 2014

Contents

Abstract ... vi

Acknowledgements ... vii

Author's contribution ... viii

Acronyms ... x

CHAPTER ONE ... 1

1.1.0 Introduction ... 1

1.1.1 Background to the Study ... 3

1. 2. Statement of the Problem ... 8

1.2.1 Research Questions ... 12

1.2.3 Purpose of the study ... 13

1.3.0 Specific objectives ... 13

1.4.0. Significance of the study ... 13

1.5.0. Scope and delimitation of the Study ... 17

1.6.0. Theoretical framework ... 19

1.6.1. Social exclusion theory ... 19

1.6.2. Exclusion and stigma ... 21

1.6.3 Cultural Construction of Biological Abnormality ... 23

1.7.0 Definitions of Terms ... 24

1.7.1 Albinism ... 24

1.7.1. Persons with Albinism (PWA) ... 24

1.7.3. Livelihood ... 24

1.7.4 Livelihood vulnerability ... 25

1.7.5. Witchcraft ... 25

1.7.6. Superstition ... 26

1.7.7. Bio-cultural exclusion ... 26

CHAPTER TWO 28

Literature Review 28

2.0 Introduction 28

2.1.0 The Social and Public Health Problem 28

2.2.1 Social Reactions to Albinism as a Congenital Concern 32

2.2.2 Stereotypes and Stigmatization African PWA 34

2.3 Bio-cultural Exclusion and Albinism as Disability 37

2.4 Albinism, Superstitions, power and prosperity beliefs 39

2.5 Status of Human Rights among PWA 44

CHAPTER THREE 48

Methodology 48

3.1 Introduction 48

3.2 Research Design 48

3.3.0: The Macro-ethnography site: Tanzania 50

3.3.1 Mwanza albinism ethnography site 51

3.1.2 Mtwara Albinism Ethnography Site 54

3.1.2 Dar es Salaam Ethnography site 55

3.2.0 Study population 57

3.2.1 Macro- and Micro-ethnographic site selection. 58

3.2.2 Sampling Participants: Mwanza Region 60

3.2.3 Study Participant Sampling: Mtwara Region 61

3.2.3. Sampling of Participants: Dar es Salaam 62

3.3 Data Collection Instruments 63

3.4 Data Collection Methods 64

3.4 Data processing and Analysis 65

3.5 Presentation of Findings 67

3.6.0 Ethical Considerations 67

CHAPTER FOUR 69
Presentation, Interpretation and Discussion of Findings 69
4.1 Introduction 69
4.2.0 Conservative Cultural Responses to the Birth of PWA 69
4.2.1 Indigenous Constructions of Albinism Aetiology 73
4.2.3 *Unyany paa*: Social exclusion and coping among PWA 74
4.1.1 Livelihood Context of Albinism Beliefs 78
4.1.2 Lifelong Stigma, Exclusion and Livelihoods Issues 80
4.1.3 Social Labelling and Livelihood Security among PWA 82
4.1.4 Emotional and Social Effects of Discrimination 83
4.2.0 Notions on Albinism and Witchcraft Beliefs Puzzle. 86
4.2.1 Albinism and Lived Experiences of witchcraft 89
4.2.2 Superstitions and mystical Beliefs in Tanzania 92
4.2.3 Perspectives of Healers on the Plight of PWA 95
4.2.4 Religious leader's perceptions 96
4.2.5 Experiences in High Risk and Low risk areas 97
4.2.6 Strategic and Practical needs 99
4.2.7 Quest for sustainable health care services 102
4.3.1 Social and Cultural Policy for Rights and welfare 104
CHAPTER FIVE 109
Summary, Conclusions and Recommendations 109
5.1 Introduction 109
5.2 Summary of Findings 109
5.3 Conclusions 115
5.4.1 Way Forward: Study Participants' Views 117
5.4.2 Policy Recommendations 121
5.4.3 Recommendations for Further Research 124

References 126

Appendix I: Interview/ Conversation Guide for Traditional ‘Healers’ [Waganga] 133

Appendix II: Informal Interview/ Conversation Guide for People with albinism and their relatives 135

Appendix III: Informal Interview/ Conversation Guide for policy makers and implementers in the Government and NGOs. 137

Appendix IV: Informal Interview/ Conversation Guide for Key general public Informants 139

Appendix V: Ethical considerations.. 141

Appendix VI: Research Permit; P.I.. 143

Appendix VII: Research Permit; C.I 144

Appendix VIII: Letter to District administrator 145

Appendix IX: Letter to District administrator 146

Appendix X: Letter to District administrator... 147

Appendix XI: Ministry of Migration: Residence Permit.. 148

Appendix XII Introduction to Administrative secretaries 149

Appendix XIII: Research Budget.. 150

Abstract

Profuse media reports and discourse on the plight of Persons with Albinism (PWA) in East Africa in the recent times raise the question of livelihood security of a minority group. PWA constitutes a group of people that are marginalized and discriminated owing to cultural perspective of biological condition. The present study draws on the social exclusion theory to characterize the social, cultural, and economic aspects of daily life struggles among PWA in East Africa. Ethnographic research design was adopted for collection of data in selected regions and micro-ethnographic sites in Tanzania for ethnography of albinism. This study explores and examines the implications of witchcraft beliefs and superstition for livelihood security of PWA. Purposive and snow ball sampling was used to collect qualitative data from sites which featured prominently in reports on insecurity and livelihood issues among PWA and their families in Mwanza and Mtwara regions of Tanzania between 2007 and 2012. The fieldwork was conducted between March and November 2011. The study revealed that stigmatization, socio-economic exclusion and extermination of people PWA in Tanzania today embody more dramatic recurrence of ancient practices affecting people with ‘abnormal’ physical characteristics. It was found out that albinism makes people victims of culturally constructed stigma and inauspicious stereotyping or prejudice related to perceived congenital anomalies. Albinism identifies luminal and ambiguous human beings with ambivalent mystical power. However, witchcraft beliefs and superstitions regarding albinism also epitomize the overall informational deprivation and experience of livelihood insecurity. Economically and socially deprived people seek alternative ways of knowing phenomena and securing livelihood by relating their experience to mystical beliefs and superstitions. People with albinism are either targets for preparation of magical portions for prosperity and wealth or scapegoats for perceived misfortunes in collective life course. East African governments have the responsibility to protect PWA as a threatened minority population of citizens. There is need to sensitize the general public, entrepreneurs, traditional healers, politicians, and local opinion leaders about the fallacy of numinous power in albinism. More persuasion, awareness and human rights advocacy are imperative for protection of PWA and improvement of their lives. Governments and other stakeholders need to recognize the condition of PWA as a public health and social problem and redress it. Improved education and socioeconomic empowerment programmes are necessary to ameliorate the livelihood of People with albinism. There is need for initiatives to enhance the government responsibility to protect PWA as minority citizens. Similarly, Tanzania and other countries in East African, Great Lakes region and Southern need to investigate the international dynamics of body parts trafficking that involve persons with albinism.

Acknowledgements

We are deeply indebted to many organizations and individuals without whom this study would not have been accomplished. First, sincere thanks go to the Department of Research in Catholic University of Eastern Africa (CUEA) for generously funding this study. Rev. Dr. John Lukwata, and Prof. Maurice Amutabi, the then Director and Deputy Director at the department respectively were very supportive since the inception of the research the whole research process to its completion. We appreciate the seminars organized by the department during conceptualization of the study, debriefing and dissemination of preliminary findings. These events were very useful for reflection and feedback that contributed immensely to the current version of the study.

The Tanzania Commission for Science and Technology (COSTECH) endorsed this study and the fieldwork between March 2011 and March 2012. We specifically would like to thank Mr. M. Mushi Mashuhuri, Senior Research Officer at COSTECH for his communication about the research permit and facilitation of the application process. COSTECH was also instrumental in mediating our introduction to the regional hierarchy of administration in Mtwara, Dar es Salaam and Mwanza. Sincere gratitude goes to Dr. Simeon Mesaki of the University of Dar es Salaam who accepted the request by COSTECH to be our local contact person for the ethnography. His contribution to our field entree, rapport building and additional insight to the study are highly appreciated.

We would like to thank our field assistants for the role they played in guiding and interpretation whenever it was necessary. First, many thanks to Mr. Mustapha Suleiman Kazumar the field assistant who facilitated the ethnography in Mtwara-Mikindani and Masasi Districts; Southern Tanzania. Mustapha eased the data collection process undertaken by the principal investigator in Mtwara region. His knowledge of the area and dedication to the fieldwork made the access to many study participants and sites possible. Mr. Ferdinand Sakali of St. Augustine University of Tanzania (SAUT) in Mtwara facilitated contact with Mustapha and the the first key informant. Tanzania Albinism Society (TAS) officials in Mtwara, Masasi, Dar es Salaam (Ocean Road Cancer Institute), and Mwanza played an invaluable role in introducing us to most of the Persons with Albinism and their families who

participated in this study. Only a few of the TAS officials and those associated with *Shirikisho la Vyama vya Watu Wenye Ulemavu Tanzania [SHIVYAWATA],* that is, Association of Organizations for People with Disabilities in Tanzania; who facilitated this study can be mentioned by name. Among these, we thank Mr. Khalid A. Chimomo, the secretary, TAS-Mtwara branch, Ms. Zahara Issa Mohamed (Mtwara) and Abdul Liwa, secretary, TAS-Masasi branch. In Dar es Salaam special thanks go to Ms. Ada Ali Sembo, the Secretary General, and Mr. Ernest N. Kimaya, the Chair Person TAS. We owe great appreciation to Mr. Alfred Kakinda and Ms. Josiane Mwanaisha Mwali) who served as the research assistants in Magu and Misungwi districts in Mwanza region. To all these people and others we have not named, we say *Shukran* for their time, participation and assistance during the fieldwork.

We acknowledge the support and hospitality of the officials of the Under The Same Sun (UTSS) organization whom we interacted with in Mikocheni B; Dar es Salaam. Mr. Elisha Ngeleja of UTTS contributed very positively and productively to the ethnographic record in his conversations with the principal investigator. Gratitude goes to him for insights from personal experiences and UTSS perspectives. We thank UTTS officials in Dar es Salaam for their precious time, information and documentary materials.

We thank all the government officials, Persons with Albinism (PWA), their families, members of the public and all the traditional healers/medicine persons (waganga) for their participation and informative insights. For the pupils and teachers of Shule Ya Msingi, Mitindo in Misungwi, we thank you most sincerely for your stories of courage and perseverance. Mzee Tembo and 'Baba Dubwi' provided invaluable transport and orientation service in Dar es Salaam. Last but not least, many thanks to Mr. Suto J. Masika from the University of Nairobi for transcription of the massive narratives collected and preserved in voice recorder files for the ethnography in Mtwara/Mikindani, Masasi and Dar es Salaam. To all the people above and those who contributed to this study and we have not mentioned them by name, we say; may God bless you all!

Author's contribution

Benson A. Mulemi (the principal investigator, -the P.I) conceptualized and designed this study. He sought endorsement of the study by government authorities; COSTECH and the Ministry of Migration in the United Republic of Tanzania. He formulated the study instruments and updated presented the literature review and the theoretical framework. The P.I collected data in Southern Tanzania; Mtwara-Mikindani and Masasi Districts of Mtwara region, as well as Dar es Salaam. The P.I carried out the comprehensive qualitative analysis and interpretation of the data. He drafted the dissemination/ debriefing presentation and incorporated feedback into this report. The P.I also drafted and edited the final research report.

Urbanus M. Ndolo (Co-investigator-the C.I) participated in drafting the research budget and presentation of the proposal. The C.I also contributed to the initial research permit application process. The C.I collected data in Mwanza (Lake Victoria) Region and gave an inventory of extracts from the data collected in Mwanza. The P.I perused the extracts for aspects that would be suitable for qualitative analysis. The C.I also presented an outline of the actual field work process in Mwanza.

Corresponding author: Benson A. Mulemi
E-mail: bmulemi@yahoo.co.uk; bmulemi@cuea.edu

Acronyms

AIDS	Acquired Immune Deficiency Syndrome
BBC	British Broadcasting Corporation
COSTECH	Tanzania Commission for Science and Technology
CUEA	Catholic University of Eastern Africa
COMESA	Common Market for Eastern and Southern Africa
CWA	Children with Albinism
DRC	Democratic Republic of Congo
EAAA	East African Albino Association
EAC	East African Community
FGD	Focus Group Discussion
HIV	Human Immuno-deficiency Virus
LHRC	Legal and Human Rights Centre
NBC	National Broadcasting Corporation
NGO	Non Governmental Organization
NOAH	National Organization for Albinism and Hypo-pigmentation
PWA	Persons with Albinism
SAUT	St. Augustine University of Tanzania
SCIS	Small Scale Investments Scheme
SHIVYAWATA	Shirika la Vyama Vya Walemavu Tanzania
TAPD	Tanzania Association of People with Disabilities
TAS	Tanzania Albinism Society
UN	United Nations
UTSS	Under The Same Sun
WLAC	Women's Legal Aid Centre
TWLA	Tanzania Women Lawyers Association
TGNP	Tanzania Gender Networking Programme

CHAPTER ONE

1.1.0 Introduction

Human albinism is among the forms of genetically determined human variation that affect both biological (physical) and socio-cultural adaptation. A single gene affects physical appearance, which contributes to problems of socio-cultural integration and natural survival persons with albinism (PWA) and their relatives. Environmental, social, cultural and economic factors interact with the biological condition to constrain the livelihood and physical security of PWA and their close kin in Africa as in other parts of the world. This implies that, albinism; a biological trait, and environmental factors, such as sunlight expose PWA to vulnerabilities, such as skin cancer and livelihood shocks. This is often reflected in daily life struggles among the PWA and their families. Lived experiences of PWA, their kin and social networks shape the emotional and social dimensions of albinism, especially where PWA are considered as strange-looking, and have hard time living a normal life, making friends and even finding a spouse (Jolly & Plog 1976:34). Albinism, therefore entail a biologically determined variation that interact with socio-cultural and environmental factors in shaping varied forms of daily life and livelihood experiences among PWA in different societies. The scenario in East Africa in relation to the plight of PWA, and particularly in Tanzania heralds a revival of the phenomenon of exclusion based on the cultural construction of biological fitness and normalcy. However, albinism and associated hardships is not a new phenomenon in East Africa, but one of the many forms of physical deficiencies which constitute the biological basis of social and cultural exclusion in African societies.

Albinism is a biological trait that has far reaching implications for the livelihood security of affected individuals and their immediate families. While a gene affects phenotype characterization of inherent biology, cultural and physical ecological factors shape further the effects and trends in the distribution, and selection of albinism (Woolf & Grant 1962:399). Albinism and sunlight, for instance, predispose PWA to skin cancer with high chances of metastases, yet lack of pigment and culturally determined standards of beauty may lead to more hardship (Jolly & Plog 1976: 34). The biological process of trait selection that results in albinism denies victims of melanin pigment that typifies biologically normal human beings. People with this condition usually have vision problems, such as reduced sight sharpness. Physical traits, such as lack of pigmentation coupled with culturally constructed perspectives and beliefs on normalcy aggravate the hardship of PWA.

Albinism is a purely biological anomaly that affects people who may be born of normal parents. However, this phenomenon has negative consequences for the livelihood of people who carry albinism as a dominant genetic trait, yet its impact vary with cultural contexts. There are two main forms of albinism affecting human beings; *oculoctaneou*s and *ocular* albinism (Robins 2005:139). The former is the most commonly cited type of human albinism. It is a collection of biological conditions that affect coloring (pigmentation) of the skin, hair, and eyes such that the affected individuals typically have very fair skin and white or light colored hair (Parker & parker, 2007). *Oculocateneous* albinism is characterized by lack of pigmentation of the skin, hair and eyes. This type of albinism also diminishes pigmentation of the colored part of the eye (the iris) and the light-sensitive tissue at the back of the eye (the retina).

Ocular albinism on the other hand manifests itself in people with normal skin but deficient of melanin; the primary biological determinant of natural pigmentation in the eyes and skin colour. Melanin plays a significant role in the development of the eye, especially the pigmentation of the iris and fovea. The later is responsible for the development of sharpness of eye vision. This accounts for problems of vision among all PWA, which include photophobia--heightened sensitivity to light--such that persons with albinism often avoid the painful sunlight and prefer staying under shades. Persons with albinism always have problems with vision, which result from abnormal development of the retina and abnormal patterns of nerve connections between the eye and the brain (Parker and Parker 2003:123). In addition, they are susceptible to sunburn, among other physical problems, and have higher risk of skin damage and skin cancers, including melanoma, when exposed to the sun (Jolly & Plog 1976, Hong *et al*. 2006).

1.1.1 Background to the Study

Human albinism was understood in biomedical terms a century ago (c.f McLeod 2010:9) after intriguing evolutionists, explorers and missionaries for a long time. However, rumours and speculations about supernatural association of PWA have lingered in popular discourse and folklore in many cultures of the world. In late 17th and throughout 18th centuries evolutionists attempted to classify PWA a separate race of strange people, especially among predominantly black populations of Africa.

According to naturists and evolutionist of the 18th to 19th centuries, people with albinism appeared eccentric as they tended to remain indoors or in caves, due to severity of photophobia until twilight (Robins 2005). This behavior increased the mystery and mythical rumours about PWA. Arguably, the obscurity of who exactly PWA are in biological and socio-cultural terms shaped their exclusion from ordinary human lives and denial of their humanity as well as personhood. This scenario has contributed to the apparent wretchedness and struggles for life and livelihood among the albinos and their kin, particularly in their primary households. Persons with albinism (PWA) are victims of the biological condition in which the body fails to produce; due to the absence of pigment to cover the colour of blood in the capillaries. Owing to the lack of the pigmentation, "black" (African), "white" (European), and Asian albinos are light skinned. They typically do not enjoy the natural protection of eyes and the skin from the sun's effects of ultraviolet rays; causing them to squint and have poor vision (Jolly & Plog 1976:34). This constitutes the basic challenge to the daily lives and livelihood of PWA as well as their primary kin who have the task of taking care of them.

Ambivalent perspectives on human albinism are ubiquitous in past and at present global cultures. Ancient Asian societies and European cultures in the Middle Ages and Renaissance period associated lighter skin; and complexion of people with albinism with physical attractiveness, wealth and higher social status. Other traditional societies, such as the aborigines of North America and South Pacific regarded persons with albinism as 'messengers of deities' (c.f Woolf & Grant1962, Woolf 1965). Similarly, some traditional African societies construct unusual biological phenomena such as albinism as either media of divine communication and symbolism, or mysterious curses and negative omen. Human albinism presents as a bio-cultural reality, which requires a bio-cultural approach to attempts to understand local cultural perspectives on the phenomenon and responses to it. A bio-cultural perspective captures local cultural views and understanding of albinism, associated vulnerabilities, and the local practices of traditional or biomedical interventions to deal with its incidence and effects. African albinos, for instance, have unique experiences of albinism relative to those born among predominantly non-black populations in other continents. Whereas in Western societies, with predominantly pale-skinned populations, people with albinism often pass unnoticed, in sub-Saharan Africa it is the most visible of conditions (Baker *et al*. 2010:269).

The peculiar experiences of African albinos on the African continent relate to the whims their physical, social and cultural ecologies. These have far reaching implications for their daily life and livelihood struggles. In the first place, they are absolutely conspicuous in among people who are expected to be exclusively black. In this context local people are often bound to construct albinism per se a disability or an abnormality. Consequently, African albinos may consider themselves to be disabled, while other people would associate them with evil or bad omen in many local cultures. This contentious label, which is disputed in western countries (National Organization for Albinism and Hypo-pigmentation stigmatise and disadvantage PWA further.

Poverty and misconceptions about albinism worsen the victims' predicament. Many PWA are born in families that are already victims of fragile livelihoods and extreme poverty. Since time immemorial, African PWA were often victims of infanticide, murder, or neglect as phenomena dialectically associated with livelihood vulnerability. Today, many African albinos may die too soon from skin cancer and illnesses linked to this condition. The spate of murder of albinos for their body parts used in witchcraft and fortune rituals in Eastern Africa further threaten the lives of albinos, particularly in Tanzania and the Great Lakes Region. Studies and Government reports in Tanzania indicate that the country has slightly more than 180,000 people with albinism (cf. www.underthesamesun.com Accessed on April, 10, 2010).

The epidemic linked to the search of body parts from particular people for use in witchcraft and fortune rituals in Eastern Africa threaten the lives of persons with albinism, particularly in Tanzania. Discourse on resurgence of killing and dismembering PWA date to the years between 2000 and 2006, yet much of the news did not reach the public (Ntetema 2010). This is in line with the fact that in Africa, many of the killings and attacks on PWA and other persons who experience culture-bound prejudice due to their unique congenital traits are neither documented nor reported. An avalanche of reports on attacks on PWA caught public attention since the year 2007 as presented in Tanzanian, the East African and international print and electronic media. Most of the reports were popularized by the British Broadcasting Corporation (BBC), National Broadcasting Corporation, in the USA (NBC), and local news agencies in Tanzania and the rest of East Africa.

By the end of the year 2011, over 100 PWA lost their lives, with most of the murders and mutilations occurring in the Lake Victoria region of Mwanza. The victims were brutally ambushed, mutilated and their organs and body parts harvested and sold to for fortune rituals and obscurantism. Reports of desecration graves of deceased PWA, exhumation of albino corpses for their body parts were also rife since 2007 (Kiishweko 2008). A cycle of body parts and human trafficking involving PWA, with Tanzania as the perceived business nucleus has ever since extended to cross-border transactions involving Eastern Africa countries, particularly, Kenya, Rwanda, Burundi and Democratic Republic of Congo. In one incidence, for example, three men who were believed to be involved in trafficking body parts used machetes to killed an 8-year-old boy with albinism in Burundi in January 2009 and allegedly smuggled his limbs to Tanzania to sale them to witch doctors who use albino body parts for potions (Lapidos 2009). Over 35 PWA were killed in Tanzania in 2008, and this led police officials to set up an emergency hot line and a special mobile telephone program to ensure the security of PWA.

The plight of PWA that further threatens their already fragile livelihood and physical security has a regional dimension in Eastern and Southern Africa. Popular discourse on the mystery of transactions with body parts of PWA often implicate both strangers and kin, members of primary social networks and close acquaintances. The PWA-related discourse includes perceived conspiracy of primary kin and even some parents in crimes against PWA and violation of their rights. Since some indigenous African beliefs construe albinism as a manifestation of curses or bad omen--either new of hereditary-- some kin and kindred collaborate in terminating the lives of PWA discriminating against, or marginalizing them (cf O'Toole, 2009). The belief in curses, witchcraft, sorcery and mystic sources of prosperity associated with the liminality that human biological conditions engender account for most of the killing of albinos in Tanzania.

Tradition, superstition and ethnic belief systems and thought thrive beside Christian and Islamic beliefs in East Africa and the rest of the African continent. The lake region of Tanzania, particularly in Mwanza, Shinyanga, and Mara areas constitute the most insecure environments to the lives and livelihoods of PWA. Most attacks and condescending acts against them have reported in these regions more than in other areas where PWA live (The Task.net, 2010, Tamric Agency, 2000, Ntetema 2010). Those who live in low risk zones such as Mtwara in Southern Tanzania and Dar es Salaam live in constant fear owing to the sordid deaths and squalid life conditions reported about PWA in the risky areas. PWA and profit from criminal activities targeting albinos and violation of their rights. The Mwanza region of Tanzania has not only witnessed the largest number of albinos murdered, it also contains 3,000 registered traditional healers, making it the region with the highest proliferation of practitioners of indigenous health care popularly labeled '*witch doctors'* in the country (Mushi, 2009).

1. 2. Statement of the Problem

While the biological features of people with albinism (PWA) cannot be changed, environmental and cultural factors and conditions that negatively affect their daily lives and livelihood struggles can be change. However, many societies in the world are yet to change the social, cultural and political conditions that contribute to further marginalization of PWA from mainstream societies. Medical experts' natural scientists, socio-cultural policy makers have not succeeded in transforming prejudice against PWA in order to protect their fundamental human rights.

Culture change and transformation of attitudes and beliefs that dehumanize PWA can help them avoid some of the hardships they face, which are not necessarily the outcomes of albinism. Mystical beliefs, stigma and discrimination of PWA have diminished in many non-African culture areas, yet contrary to what many people know, subtle reservations exist which tend to deny PWA their full personhood and humanity. The scenario in East Africa and particularly Tanzania heralds a revival of the phenomenon of exclusion based on the cultural construction of biological fitness and abnormalities. However, albinism and associated hardships is not a new phenomenon in East Africa and the rest of the continent, but one of the many forms of physical deficiencies which constitute the biological basis of social and cultural exclusion. Albinism--a purely biological process that affecting people born of normal parents (Jolly and Plog 1976) has negative consequences on the livelihood of albinos and these vary with cultural contexts.

Persons with albinism experience of insurmountable negative emotional impacts of stigma and cultural isolation, yet social development policies in Africa do not include adequate means for the physical and socio-cultural adaptation and improved livelihood of albinos. Traditional African beliefs and cultural attitudes about albinos and their families contribute further to their social exclusion. These are aspects of the man-made part of the environment and nature, that is, cultural constructions that can be changed through appropriate education, and culture policies, but this is yet to materialize in East Africa. Abduction and murder of albinos for portions of good fortune, witchcraft, magic and sorcery have emerged in different regions in East Africa, particularly in Tanzania, replacing the traditional infanticide and other obscure and concealed practices that shortened the lives of albino children youth and rare adults in the past.

The belief that body parts from PWA have mystical power has thrived in Eastern Africa over time. This contributes to expectations of a great deal of fortune by body part traffickers. Given the struggle for livelihood in a resource poor country such as Tanzania, the trade in albino body parts presents itself as an alternative to earning a living and even becoming rich and prosperous quickly. The Majority of people in Mwanza region of Tanzania where the spate of attacks on PWA for their body parts increased since the year 2008 depend on fishing and mining gold and other minerals for their livelihood. Most of the population in this region is rural and lacks adequate contact with the modernized urban areas. As a consequence, Mwanza and other regions of Tanzania have high rates of poverty and illiteracy that affects minority groups such as PWA more than other citizens. Traditional beliefs and inclination to the authority of local healers (witch doctors) in explaining sources of hardships or misfortunes underpin the vulnerability of people with albinism today.

When African albinos survive infanticide due to superstitions negative beliefs and fear of evil that local people link to the birth of a person with albinism, they soon become prey to those who believe that albinism epitomize mystical power that can facilitate different forms of prosperity or success. In 2008 alone, over 50 cases of abduction and subsequent killing of children with albinism were reported in Tanzania, which made the government recommend that albino children would go to school under police escort (cf. www.wvwnews.net , Accessed on 16, August 2013).

Livelihood tribulations of PWA and their kin have been reported a great deal in Tanzania and other parts of East and central Africa. The magnitude of the problem can be perceived in social, cultural and political economic terms, but the claims to modern civilization and humanizing consequences of conversion to contemporary world religions in other parts of Africa and the world belie social exclusion and discrimination of cultural minorities, such as PWA. Christianity, for example, still grapples with the social implications of both witchcraft accusation and the persecution of the people perceived to be involved in obscurantism. The mystery of cartels linked to the disappearance and mutilation of PWA in Tanzania indicate that contemporary religions and agents of social development are yet to ensure the survival of types of people whom indigenous cultural beliefs deny the right to survive, or relegate them to survival struggles on an inferior plane. ‘Albino hunting’ in East Africa today therefore epitomize systems of social and cultural exclusion, further manifested in rising levels of poverty, struggle for scarce resources and power. The key question therefore is; what are the manifestations of the political economy of the unnatural selection against people with albinism in Africa today?

Few studies have focused on human albinism as both a biological and cultural problem. Available literature indicate that researchers have globally focused on understanding and attempting to resolve the biological issues human albinism (Parker and parker, 2007, Parker and Parker 2003) more that the social and cultural consequences. The central proposition in the present study is that the misfortunes of PWA in East Africa today reflect a resurgence of beliefs and practices that literally exterminated them and reinforced their exclusion from daily social life activities in traditional cultures. In addition, contemporary discourse on genetic engineering for exclusion of potentially “defective human types” from normal life course (English, 2004, Reist, 2006, Stone, 2002, Pernick, 1996) corresponds to traditional African infanticide and other practices to eliminate or discriminate PWA, which constitute unnatural selection and facilitation of survival for the fittest.

While the physical or biological features of albinos cannot be changed, environmental and cultural factors affecting their daily lives can be transformed, thereby helping PWA to avoid some of the secondary effects of their biological disability or selection. This transformation of environmental factors for the well being of PWA can be realized through the use of artifacts such as sunscreens, appropriate housing, protective clothing and cosmetics. However, PWA in low income countries of East Africa are further excluded from accessing these resources due to lack of or inadequate supply, residence in remote villages and the fact that the majority of them have fragile livelihood backgrounds. Similarly, transformations of social and cultural factors that exclude PWA from normal life remain elusive in East African societies. This particularly the case due to low awareness about albinism, deep-seated myths, superstitions and traditional beliefs associated with albinism and inadequate political as well as social will to protect albinos whose basic rights are violated due to popular beliefs that affect them.

Modern ethical standards, advocacy for universal human rights and improved lifestyles tend to favour the survival of many African albinos beyond cultural selection in their infanthood and childhood. However, the resurgence of witchcraft beliefs, superstition, magic and concomitant perceptions of mystical power and personal prosperity that can accrue from albino body parts adds to negative consequences of natural biological selection that threaten bio-cultural adaptation of PWA. Victims of albinism remain an unfortunate socio-cultural minority in Africa today, despite of the advancements in medical and healthcare technology, social development and human rights initiatives. They have special needs and suffer double exclusion—biological and cultural—from normal life without meaningful recourse in as the reports from Tanzania and other parts of East Africa since the late 1990s indicate.

1.2.1 Research Questions

In order to put the main livelihood issues among people with albinism and their families in perspective, this study revolves around attempts to answer the central question: how do cultural beliefs and superstitions about human albinism constitute a revival of indigenous forms of exclusion and that affect the livelihood and quality of life of PWA in East Africa? The study pursues this question further through these sub-questions: How do albino persecutions in Tanzania characterize different levels of poverty and struggle for resources and power in East Africa? What are the social and economic implications of the albinism stigma for the affected people's livelihood and social development? In what ways can social and cultural policy in East Africa and particularly, Tanzania integrate people with albinism in mainstream social and economic life? How do lived experiences of albinos and their close kin characterize suffering due to superstitions and witchcraft beliefs in East Africa?

1.2.3 Purpose of the study

The main purpose of the ethnography was to explore the patterns of beliefs and superstitions that affect the livelihood and quality of life of persons with albinism and their families in East Africa. Theories of stigma (Goffman 1963, 1997), social and bio-cultural exclusion are used in the ethnography sought to explore the adversities that people with albinism encountered and how they attempted to cope with them.

1.3.0 Specific objectives

In relation to the main purpose of the study above, the ethnography set out specifically;

i. To examine the relationship between the struggle for resources and power and livelihood security of persons with albinism (PWA) in Tanzania.
ii. To determine the nature and consequences of stigma and discrimination against PWA on their livelihood and daily lives.
iii. To describe the lived experiences of PWA in relation to witchcraft beliefs and superstition about albinism in Mwanza, Mtwara and Dar es Salaam in Tanzania
iv. To assess the status of social and culture policy for the integration of Persons with albinism as a minority population in Tanzania and East Africa in general

1.4.0. Significance of the study

The plight of albinos in East Africa today is an issue that relates to contemporary discourse on integration of social and cultural minorities in national, regional and international development processes. Ethnography of the experiences of albinos in Tanzania brings the fore a case study of people who bear marginalisation and discrimination in the modern world due to their biological characteristics. Their genotype, which makes them physically conspicuous among their own African nationals disadvantage them as a minority social, cultural and biological group without established mechanisms for their meaningful integration in society. This study, therefore adds voice to the plight of persons with albinism within national and regional integration discourse in East Africa where current development initiatives pay inconsequential attention to and understates the livelihood issues of PWA. This study hopes to contribute vital ethnographic data on the (mis)fortunes of African albinos. Extant information on the adversities of albinos in Africa reflects only cursory media reports with little anthropological and sociological analyses.

Government and media approaches to the plight of Persons with albinism in Tanzania and the rest of East Africa often fail to prevent their murder, persecution and social exclusion. Prior to the present ethnography, the way the issues affecting PWA were reported indicated some concern about their discrimination and persecution as a social and human rights violation issue, but did not emphasise the anthropological understanding of the underlying norms and values that relate to killings and discrimination of PWA. Media reports on this matter show only part of the problem, at the height of the political visibility and public outcry of persecution of PWA, yet this is apparently a resurgence of an ancient malevolent practice in Africa (Curran, 2009, 2011). This study attempts to fill the gap in the knowledge about the fortunes and misfortunes of PWA by highlighting the anthropological undercurrents of albinism local responses to its consequences. This ethnography hopes to lend voice to the sufferers—the persons with albinism and their close kin--who experience marginalisation as victims and care givers in complex physical, economic and cultural environments in East Africa.

This study set out to render an ethnographic analysis the political economy of discrimination of people with albinism as one among socio-cultural minorities whose congenital traits shape their discrimination. It analyses the ways in which current problems facing PWA is deeply embedded in indigenous cultural attitudes norms and beliefs among ethnic Tanzanians and related African societies. In the present study, the ethnographic analysis is presented as the forgotten dimension in attempts to understand and address the consequences of albinism, which is both a biological and socio-cultural phenomenon. While PWA are not necessarily disabled, traditional African cultures construe them as such. This experience compels many of the people with albinism in Africa to contend with the disability label. Owing to this the international advocacy for the ameliorating the quality of life of people with disabilities include those with albinism. This study is contributes to the body of knowledge that is necessary for the realisation of the vision of the International Year of Disabled Persons in 1981, The World Programme of Action concerning Disabled Persons in 1982, and the development of the Standard Rules on the Equalization of Opportunities for Persons with Disabilities (UN 1994).

The present study presents an important point of reference needed awareness about bio-cultural perspectives on disability and evaluation of national and international programs for confronting the limitations of biological and culturally constructed disability on human freedom. The case study of PWA in East Africa, and particularly Tanzania, is a contribution to minimizing the dearth of ethnographic record on minority rights and livelihoods. Contrary to what many people know, local belief systems and culture-specific stigma doubly disadvantage PWA. This study therefore underpins current discourse on basic human rights of social and cultural minorities. Dissemination of the findings of this study will add a new perspective integration of PWA into mainstream development as an exemplar of neglected social and cultural minorities in East Africa. The need for integration and care of the disadvantaged people in East Africa reflect the imperative for moral and political commitment to promotion of social justice.

The effects of human albinism have both socio-cultural and medical dimensions, but the later is hardly assessed in detail. The data presented and analyzed in the current study is opportune to form the basis for increased awareness of and public health interventions for albinism in order to better address the medical, psychological and social needs of this vulnerable population. Albinism is an emerging public health problem that requires interdisciplinary partnership to deal with. The innovative character of the present study lies in its ethnographic approach. The ethnographic data presented herein can inform appropriate public health interventions that would be relevant for dealing with problems that PWAS experience in the cultural contexts of East Africa.

This ethnographic study is intended for dissemination to local audiences in East Africa and beyond. This will create awareness about the persistence of indigenous beliefs, superstitions and attitudes that increase livelihood vulnerability among PWA and their families. The monograph is therefore a significant contribution literature that can facilitate re-focusing promotion of the well being of PWA and community education about their livelihood potential and social protection. One of the key propositions of the current work is that the revival of fanciful beliefs about and discrimination of PWA in East Africa today belie the obligation of governments, educators and religious functionaries to alleviate social suffering and protect citizenship of all categories of people. Therefore, this study gives voice to PWA and their families as they seek justice and improvement of their quality of life.

1.5.0. Scope and delimitation of the Study

The study explored the experience of people with albinism in sites that appeared most frequently in both print and broadcast media as well as community reports since 2005. The research concept was formulated in July 2010, with follow-up workshop discussions organized by the Department of Research at the Catholic University of Eastern Africa (CUEA). This marked the beginning of secondary data collection, literature review and content analysis on the daily life and discrimination experiences of persons with albinism in Africa and specifically East Africa. Particular focus was on Tanzania, which dominated the discourse on issues in daily lives of PWA as reported in international and regional media.

Mwanza region (Lake Victoria region), Southern Tanzania Region (Mtwara, Masasi and Mikindani Districts) and the city of Dar es Salaam (and its environs, especially Mikocheni B, Kwa Warioba and Ocean Road Cancer Institute) were identified as the main sites for the ethnography. It was hoped that the ethnographic record in these sites would lead to more in depth investigation on witchcraft and magic beliefs and superstitions related to human albinism. The main focus was on how these aspects affect the livelihood of PWA in Tanzania. We intended to use this as the point of departure in extending the investigation to PWA and other people similarly victimized people in selected sites in Kenya, Uganda and the Great Lakes region at a future date.

Reports on superstition, magical and witchcraft beliefs involving PWA in Tanzania and regionally have often culminated with Tanzania as the epicenter of reported cased of obscurantism and tribulations affecting people with albinism. Therefore information on the study on vulnerability of albinos was derived from but not limited to the geographical or political boundaries of Tanzania. However, detailed description experiences of PWA in the wider East African Community area is envisaged in a second phase of this ethnography.

This study focuses on an ethnographic record and analysis of human albinism relative to the discourse on superstition, witchcraft and magical beliefs. The proceeding ethnographic analysis is embedded in the conceptualization of mystical power in albinism, which local people paradoxically link with both the quest for economic and political prosperity, and bad omen. It also analyses issues in societal well being of albinism victims and their families and superstitions regarding the birth of albinos and their personhood. An attempt is made to integrate the analytical perspective of bio-cultural anthropology in discussion of local constructions and responses to persons with albinism. People with albinism, their kin, albino welfare organizations, traditional healers and members of the general public were respondents and informants in this study. Some of the data collected and generalizations made in the study reflect the temporal, cultural, social, economic and political circumstances that were distinctive for Tanzania and its ethnic groups between 2005 and 2014. The year 2005 typified a climax of the avalanche of reports about persecution of persons with albinism (PWA) in Tanzania and neighbouring countries. This motivated the present study and prolonged curiosity about the experiences of PWA until the completion this monograph in 2014. A significant part of the findings in this study are fairly representative of the general experience of PWA and their families in other parts of East Africa, and indeed some parts in the rest of the African continent. Reactions to human albinism reflect shared beliefs and perceptions about biological abnormalities in African worldview represented in majority of societies in sub-Saharan African as the available literature indicate. This study therefore is conceptually representative of African cultural perspectives on human albinism. This does not preclude the fact that perspectives on PWA and the efforts to integrate them in modern African societies have been improving since pre-colonial times to date.

1.6.0. Theoretical framework

This study draws on Social Exclusion Theory (Biggs 2004, Bonner 2006) to explain the experience of People with Albinism in Tanzania and suggest ways to deal with its biological and socio-cultural consequences. The key theoretical concepts from this framework are exclusion, stigma, marginalization and social deprivation, which this study links to the bio-cultural perspective in anthropology.

1.6.1. Social exclusion theory

The social exclusion theory presents a paradigm for the study, description and explanation of biological, cultural, economic, and political dimensions in marginalization, discrimination and suffering of people with albinism(PWA) in East Africa. Social exclusion is a process of change in the whole society that has negative consequences for some of the people (Byrne 2005:2). The results of social exclusion include failure of integration of some people into employment and with common social arrangements including family, friends and local community. Social exclusion is often visible in existence of disadvantaged groups uniquely characterized by unemployment, poor skills, low incomes, poor housing, experience of high crime, bad health and family breakdown (cf. Bonner 2006:4). These issues affect both individuals and groups in rural, urban and suburban areas alike. According to Madinapour *et.al* (1998:22) social exclusion is a multi-dimensional process, in which various forms of exclusion are combined. The multifaceted nature of exclusion include low participation of some segments of society in decision making, political and peace building processes, as well as unequal access to employment and material resources. Similarly, socially excluded people experience low integration into common cultural processes and institutions that define their ethnic and national identities.

While social exclusion can affect anyone, some people are more vulnerable than others due to their social, ethnic, and biological attributes. People with certain perceived cultural, economic and political disadvantages and exceptional congenital experiences are likely to unduly suffer social exclusion. In this regard, Percy-Smith (2000) defines social exclusion in terms of poverty and spatial issues and identifies seven dimensions of social exclusion. The first entail the economic aspect related to variables such as enduring unemployment; workless households and income poverty as distinct. The second is the social side of exclusion, which may be manifested in homelessness; crime and disenchantment among the youth. Aspects such as disempowerment; lack of political rights; and alienation from/lack of confidence in political processes characterize the third dimension, that is, the political dimension of social exclusion. The fourth element epitomizing social exclusion is the neighborhoods where affected people live. Socially excluded people often inhabit squalid housing structures in neighborhoods with manifest environmental degradation, poor hygiene and sanitation. The fifth aspect of exclusion is defined in terms of the condition of individuals concerned. In this sense, exclusion is manifested in mental and physical ill health and educational underachievement. The sixth aspect of social exclusion, according to Percy-Smith (2000) is spatial. This involves marginalization of vulnerable groups in social spaces and their limited or lack of participation in activities in these spaces. Finally, the group dimension of exclusion involves the concentration of above characteristics in particular groups, such as the disabled, stigmatized, elderly, ethnic minorities and those in lower echelons of social hierarchy. These characterizations of social exclusion aptly depict the experience of people with albinism as socio-cultural minorities in rural, peri-urban and urban areas in East Africa.

People with albinism are among the groups in African societies that are excluded from normal daily life due to their biological or physical condition. The perception that their body parts are precious magical products does not only discriminate and exclude them from the normal life; but also creates anxiety, fear and denial of freedom of movement and association. This constitutes disaffection that leads to psychological distress since PWA become suspicious and doubt the worth of their personhood. The exclusion contributes too extreme poverty and suffering since they cannot participate freely livelihood activities. More significantly, social exclusion of PWA characterizes inadequate access to livelihood assets. Among the assets that are scarce among PWA due to social exclusion are income generating work, and assistance, information, education, health services and employment opportunities as aforementioned. Poverty and poor living conditions intensify stigmatization, despair and hopelessness, leading to further social exclusion (Bonner 2006). Social exclusion is therefore related to conceptualization of stigma, which often explains the predicament of PWA.

1.6.2. Exclusion and stigma

Stigma has its roots in perceived ‘differences’ and it triggers pain and emotional hurt linked to others’ pity, fear, disgust and disapproval of this difference (Mason et. al. (2001:2). Stigma affects the stigmatized persons whether their differences relate to personality, physical appearance, illness and disability, age, gender or sexuality. Stigma can be therefore be defined as a trait that serves to discredit a person or persons in the eyes of others (Franzoi, 1996, Reidpath *et. al.* 2005). Attitudes towards any discreditable attribute vary with cultures through time and space. The stigma associated with human albinism in Africa, for example, is not of the same magnitude as it would be among predominantly white populations. Stigma is also culturally defined, and variation is evident in the ways in which particular attributes are either accepted or otherwise between culturally diverse groups (Mason *et al*. 2002:1).

The impact of stigmatizing attitudes on the stigmatized individual shows a discrepancy in form and intensity. The reaction of people towards those they stigmatize often focus on their visible or less obvious unusual difference, and thus there are forms of discrimination and prejudice which can be identified in the interactions between the 'normal' and the 'discredited' (Goffman, 1990). Discrimination and prejudice separate and exclude individuals from society and from many of its benefits, such as equitable access to resources and services like housing, education, health and social support. This constitutes obvious or subtle restriction of an individual's or groups' full membership of community. Consequently, stigmatized do not enjoy access to social goods and resources as other members of society. This in turn has a negative impact on the health and wellbeing of the excluded groups. It is argued here that community In other words, stigma entail the fact that esteemed membership to a socio-cultural group is determined on the strength of the perceived social worth of groups and individuals and stigmatization is the marking of individuals and groups who are 'unworthy' of social investment (Reidpath *et. al*.2005:469-670). This type of discrimination constitutes a form of social exclusion. Stigma and social exclusion demoralize individuals and cause low self-esteem, poor social relationships, isolation, dejection, and may result in self-harm.

Groups as well as individuals who are stigmatized detest tactless conduct towards them and this reinforces social withdrawal, self-pity and inadequate social, economic and political integration. The social exclusion theory and the related conceptualizations of stigma are used in this to examine the implications of exclusion of people due to cultural ideologies regarding a biological condition such as albinism. The analysis in this study therefore links the theoretical concept of exclusion to the bio-cultural perspective, which presents a comprehensive view of human beings (c.f. McElroy1990: 244).

1.6.3 Cultural Construction of Biological Abnormality

The bio-cultural perspective shows that biology and culture are intertwined in a continuous feedback relationship of ongoing exchange (Lock 1998:410). This approach examines the developmental and environmental processes that bring about human variation (Bogin 1999, Worthman, 1993). The processes, for example shape differences between PWA and people with appropriate amount of melanin. However, this study contends that the plight of PWA manifest double exclusion—biological or natural and cultural. The rationale for conceptualization of exclusion in view of the biocultural perspective is that biology and culture are inseparable in the quest for broad study and understanding of human social facts and ideologies. The biocultural framework upholds the goal of comprehensive ethnography and holism espoused in anthropology (Sievert, 2006:15).

The bio-cultural approach is used in the present study as a feedback system through which we explore how biological and cultural attributes interrelate. The main premise here is that biology shapes particular behaviours and reactions such that the behaviors in turn influence natural life experiences and livelihood security of persons with albinism (PWA). Through the understanding of both the biological and cultural implications of albinism and its personification, responses to this genotypic trait are essentially cultural outcomes. Thus, the behavior and responses to PWA vary with socio-cultural, economic and political contexts. The bio-cultural perspective in this ethnography calls attention to the need to reflect on how cultures construct human albinism and associate it with either positive regard or stigmatization.

1.7.0 Definitions of Terms

1.7.1 Albinism

Albinism refers to a collection of congenital conditions characterized by little or no pigment in their eyes, skin, or hair. It is a condition associated with defects such as:- photophobia (high sensitivity to blight light), nystagmus and astigmatism, making persons with albinism (PWA) susceptible to sunburns and skin cancer if over exposed to sun rays and heat.There are different types of albinism and the amount of pigment in the eyes and hair may vary. Albinism affects people from all races and other mammals and reptiles. Many children with albinism are born to parents who have normal hair and eye color for their ethnic backgrounds.

1.7.1. Persons with Albinism (PWA)

Persons with albinism (PWA) are people (infants, children, youth and adults) with visible and or less obvious albinism traits. They are also referred to as albinos, although many people today find the later term untactful and somewhat disparaging social label for albinism victims. They have inherited deficient genes that do not make the usual amounts of a pigment called melanin. There are some variations in the body traits or physical characteristics depending on the modal phenotype of their ethnic or racial type. A person with albinism generally has pale skin, light hair, pinkish eyes, whose skin, and weak vision when exposed to bright light.

1.7.3. Livelihood

The livelihood means the source of supports for peoples' life or existence. It denotes the mechanisms by which people attain their subsistence. It further denotes a state of being able to live and a set of activities that one engages in for survival and social security. This includes means of securing the basic necessities of life, such as food, water, shelter and clothing. The activities are usually carried out repeatedly. Conceptualization of livelihood includes access to social and cultural capital, control of resources. In other words, livelihood consists of the capabilities, material and social resources and activities required for a means of living (Chambers & Conway, 1991).

1.7.4 Livelihood vulnerability

Livelihood vulnerability refers to the inability of people to remain resilient in times of economic and social hardships. These could result from seasonal changes, natural disasters, conflicts and economic fluctuations. The vulnerability of PWA is associated with inadequate social support and social protection policies that expose them to the vagaries of traditional ideology couched in superstitions, witchcraft and magic beliefs. In this study, livelihood vulnerability and insecurity among PWA is mediated by the general economic hardships with limited national mitigation policies. Persecution of PWA is therefore part of mistaken coping strategies among misinformed perpetrators, who need to develop new livelihood strategies in order to survive. Persons with albinism are particularly vulnerable in East Africa due to a combination of environmental and sociological factors, which have served to repress this group and prevent mobilization (Allen 2010). A combination of biological, cultural, social and medical conditions shape daily life vulnerability of PWA. Thus people with albinism are an example of a socio-cultural minority group that is further defined by perceived biological and medical challenges.

1.7.5. Witchcraft

In this study, this term is applied to mean application of supernatural or extraordinary powers to cause bad (evil) reaction on another person or his/ her situation. It is a form of magic in which a person harms or injures another or others using personal powers or related objects of power. Witchcraft connotes actions associated with negative outcome/ effects. It further denotes use of magical powers to spell bad outcome or reactions on others or their negative schemes; for instance to harm people or their property. It operates on belief that one has authority to influence bad deeds on others. Witchcraft is therefore a cult in which people believe in super-ordinary powers to inflict harm on other people and their property based on wishful thinking. Witchcraft, then, is the practice of secretly using supernatural power for evil– in order to harm others or to help oneself at the expense of others (Tebbe 2007: 190)

1.7.6. Superstition

Superstition refers to a notion that is not necessarily based on pragmatic reasoning regarding supernatural powers that could alter either man-made and/ or natural realities. It is extreme fantasy in an attempt to seek and explain patterns in occurrences. Superstitions often occur in situations of uncontrolled uncertainty, where the reason to the link between occurrences is not well understood. In this study, we take cognizance of both subjective and objective definition of superstation. Subjectively, it is the disposition or tendency to ascribe phenomena which admit of natural explanation to occult or supernatural causes; or objectively, it is any system of religious belief or practice which manifests such a tendency. Superstition is thus a belief that does not have immediate empirical foundation in things or phenomena which, although owing their origin to perfectly natural and logical causes, are attributed to some supernatural force or power, the results of which are distorted by popular imagination and fantasy (c.f. Bonnerjea, 1927: 3, Mulemi 2004).

1.7.7. Bio-cultural exclusion

The term bio-cultural exclusion is used in this study to depict the synergy between the disadvantage of albinism as a biological condition, and the culturally constructed unfavourable notions that further isolate PWA from ordinary life. Thus bio-cultural exclusion depict the process through which PWA are doubly prevented from participating in ordinary life owing to the biological trait to which human responses vary with cultures. This is a process in cultural labelling of albinism and its biological whims prevent which PWA and their families from the advantages of 'normal' mainstream life that people not affected by the biological condition have relative easier access.

This study focuses on how cultural traditions, beliefs and social conditions can both exacerbate or ameliorate the livelihood vulnerability and human rights of PWA. It analyses the situation of persons with albinism in the wider context of the struggle for livelihood security in East Africa, and specifically in Tanzania.

The present ethnography considers issues in quality of life, health, fragile livelihood among people with albinism and their families. It proposes a conceptual perspective of bio-cultural deprivation and exclusion. This is an ethnographic analytical framework for status of healthcare and integration policy for PWA. It delves into how natural and socio-cultural selection affects the survival and fitness of PWA for livelihood autonomy.

CHAPTER TWO

Literature Review

2.0 Introduction

There is paucity of social science literature on human albinism in Africa. The avalanche of internet information by human rights activists and media reports is deficient of evidence for sustained sociological research and comparative ethnography of albinism in East Africa and the entire continent. Most of the available literature presents the psychobiological, genetic and biomedical dimensions of albinism with negligible ethnographic analyses (see for example, Parker and Parker 2003, 2007). This chapter reviews literature on cross-cultural beliefs and superstitions about human albinism and their consequences for livelihood and quality of life of persons with albinism (PWA). It focuses on responses to albinism and PWA in the global, African and East African contexts. It examines the link between livelihood insecurity and perceived discrimination of PWA. Similarly, the review traces how notions of power, poverty and struggle for livelihood resources shape the discourse on human albinism and affect the daily lives of PWA in Africa. Drawing on the theoretical framework discussed in chapter one, this chapter synthesizes researches and discussions on the social and economic implications of stigmatization of PWA. Albinism as a social problem and initiatives for improvement of the lives of PWA are appraised.

2.1.0 The Social and Public Health Problem

Studies from sub-Sahara Africa show that the prevalence of human albinism is high, with an approximate ratio of 1:12,000 (Lund 2005, Lund & Gaigher, 2006), or the overall prevalence rang of 1/5,000 – 1/15,000 (Hong *et al.* 2006). In Tanzania the prevalence of human albinism is estimated at1:200. This is very high prevalence in a single African country, compared to world figures (cf. www.underthesamesun.com, accessed on September 9, 2013). The estimated high prevalence of albinism in Africa suggests that the population of people living with albinism in Africa is could reach tens of thousands, contrary to what many people know today. The perceived high prevalence of this condition in Tanzania may point to both cultural and biological dynamics, such as inbreeding, which may contribute selection of the albinism trait (Woolf 1965, Woolf and Grant 1962). The knowledge of such a situation calls for urgent awareness creation about albinism, and support for public health interventions for people living with albinism. This would help in addressing better the medical, psychological and social needs of this vulnerable population (Hong *et al*. 2006).

Persons with albinism in African countries have a very different life situation than people with albinism from countries where the majority of the population is Caucasian or light skinned. In the latter contexts, there are high levels of awareness about the condition and requisite medical care (cf. Braathen 2005:6). Levels of social integration, medical and social care of PWA vary with cultural ideologies about the biological anomaly and level of socioeconomic development respective societies. PWA in African settings still need more attention with regard to medical and social care and awareness campaigns for their integration into the society (cf. Hong et al. 2006). Albinos of Caucasoid extraction or from Western countries are not as conspicuous and easily stigmatised as those in Africa countries where the majority of the indigenous inhabitants are black. Nigerian Igbo albino subjects, reported ‘demerits’ of living with albinism in their environment, which included conspicuous colour, delicate skin which blisters under the sun, defective sight, interpersonal, especially heterosexual, problems and society's unkind attitude(Ezeilo 1989:1129). Lund and Gaigher (2002) documented similar patterns of stigma and discrimination in a self-report study with children with albinism in a special school in northern South Africa.

Differences in appearance in predominantly black environments couple with low awareness about albinism to shape stigma that African PWA have to endure (Hong *et al*, 2006). Eighteenth century discourse on ethnography of albinism depict the challenge the ambiguity of this phenomenon has posed in people's quest to explain human variation over time. Before the eighteenth century, Western naturalists, explorers and philosophers were familiar with accounts about strangely pale, night-dwelling people living on the African continent (Curran 2009). Their incongruously white faces, bodies and eyelashes tended to confirm conjectures about the existence of 'strange beings' beyond the western Christian civilization. Perspectives on the personhood of PWA during the European Age of Enlightenment point to a similarity with lingering prejudice about albinos in past and present African societies. To the early explorers and thinkers, encounters with PWA confirmed the perception of African semi-monstrosity like pigmies or long-tailed humans (Curran 2009:155). Coincidentally, the views of eighteenth century naturalists about albinism in Africa reflect the traditional African association of human albinism to evil or curses. Ambiguity of African albinos prompted evolutionists such as Buffon to support argument Africans being denigrated forms from a prototype white variety. In addition, the diminished population of PWA in Africa would be explained by the view that inhabitants of Africa did not allow them to multiply, or procreate as they were subjugated at court, hunted like animals, or isolated in groups (Curran 2009: 154).

Traditional cultural ideology and superstition rather than appropriate genetic explanation of the etiological aspects of albinism shape the experience of inadequate social integration of albinos in Africa (Lund 2005). Lack of awareness about the biological causes of albinism fuel social discrimination of PWA and their kin, specifically their mothers. Low knowledge about the origin of albinism is widespread in indigenous African and non-African cultures. In a study of albinism among Indians in Arizona and New Mexico, Woolf (1965: 29), for example stated that: Hopi, Jemez, and Zufii Indians do not understand the origin of albinos and a variety of explanations are given, such as the breaking of a taboo by one of the marriage partners or the mother having sexual relationships with a white person. This scenario over five decades ago among aboriginal North Americans tends to be replicated in African beliefs about albinos in the past and present millennia. Indeed, the social difficulties of being an albino in a dark-skinned population continue to have heavy impacts in African countries today. People with albinism develop anxieties and experience marginalization because of their biological weakness and social rejection

Low education especially in biological science constrains awareness and understanding of genetic inheritance. Owing to this numerous traditional myths and superstitions about albinism and other physical differences thrive. As it is explained later in this chapter, for example, some traditional African beliefs present albinism and other unusual physical characteristics as a consequence of punishment from the gods for an ancestor's wrongdoing (Onkoro 1975). This implies that discrimination of PWA is rooted in local social and cultural systems and often compromises the quality of life among the victims and their families. While people with albinism are very likely to have a reduced fitness as compared with non-albinos in all populations (Woolf &Grant 1962), they are not disabled *per se*, and have normal intelligence (Lund & Gaigher 2002).

Persons with albinism all over the world acquire socially disability labels from their cultures. Similarly, biomedicine constructs disability in relation to perceived biological abnormality; hence the social disability label may coincide with albinism as a medical problem (Michalko 2002). However, health professionals and activists have not yet reached a consensus as whether albinism *per se* constitutes disability or not. All perspectives taken in attempts to understand human albinism point to the fact that biology, culture, and society shape the condition as both a social and public health problem. People with albinism suffer the consequence of both genetic deprivation and the social construction of their disability. Cultural assumptions and stereotypes put either limitations and stigmatising advantage or weakness on their daily lives and integration in ordinary livelihood activities. In Arizona, United States of America, for Example, Woolf and Grant (1962:391) found out that traditional Hopi Indian ideology on biological/phenotypic anomaly attached some religious significance to albinism, suggesting the possibility of cultural selection for the gene in this population.

2.2.1 Social Reactions to Albinism as a Congenital Concern

Literature on experiences of discrimination and stigma among persons with albinism in Africa begin at birth (Kromberg, 1987). This phenomenon begins with the questioning reactions of mothers, birth attendants, and mothers' as well as their relatives' wider social networks. The birth of a baby with congenital abnormality shatters expectations of having offspring considered in local cultures as perfect or normal. This means that albinism like other perceived congenital defects may trigger a series of reactions and feelings, which may require a process of adjustment where personal and social expectations must be re-aligned and re-evaluated (Farrell and Corrin 2001: 53). People accept what their cultures define as normal; both in social behaviour and phenotype traits. This means that notions about normalcy with regard to congenital traits like albinism vary with local cultures, mythology, religious beliefs and historical progression.

Stigmatizing responses to PWA are expected due to the fact that albinism is an obvious congenital abnormality. Conversely, the etiology of human albinism is not intelligible to many people affected by the condition in past and present African societies. Over time, this condition became both difficult to understand and culturally unacceptable in many African cultures. In this sense, responses to PWA are culturally defined and socially constructed. Variations in these responses are often evident in the ways in which particular congenital attributes are either accepted or otherwise between culturally diverse groups (cf Mason *et al* 2001:2). Persons with albinism and their families generally experience bigotry from the community. Traditional myths about the aetiology of albinism often sustain stigma and psychological distress among PWA, their primary kin, members of their genealogies and primary kin (McLeod 2010). In Uganda, for instance, most children with albinism are immediately exposed to discrimination from within their very own families since the time they are born (Allen, 2010:8). As in many traditional and contemporary African societies, subtle or overt discrimination of children with albinism in Uganda may come from their parents and other family caretakers. This implies that the exposures of people with albinism to inhumane treatment in African societies begin from an early age, and this has indelible consequences for the esteem and personhood of PWA effects (c.f. Baker et. al. 2010:169).

Discriminatory and stigmatizing reactions about perceived congenital abnormality, such as albinism, are not unique to traditional African societies. In the ancient Greek society, for example, congenital abnormality was seen as a sign of divine retribution, for transgressions in an earlier life. Similarly, decrees to head of families to kill children with congenital deformities were common among ancient Greeks (Garland, 1995). Cases of mothers throwing their own albino children away, killing or abandoning them because of the fear and stigma associated with albinism are common in the narratives in Africa (Cf. Allen, 2010:8, Braathen, 2005, Stensson 2008, Larson, 2011). An African father in the past was more likely to abandon a child with albinism and his or her mother or kill the child, due to the belief that the mother might have been unfaithful (Ntinda, 2009). The pattern of discrimination and social exclusion culminates in livelihood difficulties among PWA. As an example, they are constrained in finding proper employment, due problems in accessing formal education and training. Similarly, stigma and discrimination reduce chances of PWAs to find marriage partners compared to the rest of the population (Hong *et al*, 2006, McLeod 2010).

2.2.2 Stereotypes and Stigmatization African PWA

Due to public curiosity, socio-cultural constructions of normalcy persons with albinism (PWA) are victims of negative stereotypes and stigma. Social and linguistic labels abound in African languages to emphasize the uniqueness of PWA, which contribute to their tacit or overt social exclusion. Along the East African coast, for instance, the Kiswahili language term, '*Zeru zeru'*, is used refer to a person with albinism. The term denotes a person with black and white patches on his or her body. Similarly, the term *'Mzungu*' (white person) is often used to disparage a person with albinism.

Among the Bamileke of Cameroon, the whiteness of a person with albinism links him or her to the spiritual world of the deceased. In popular discourse, therefore, a person with albinism would be referred to as *meffu*, which translates to 'dead' (Baker & Djatou 2007). Stigmatizing labels exist in other indigenous ethnic groups in Cameroon pointing to the personhood of PWA as strange or even celestial beings. These labels include *fogtab gab* ('white' or 'chicken'). The Bakweri and Pahouins of

Central and Southern Cameroon include notions of *mongou* ('strange 'being'), *ko* ('different being from others)'.or *nnanga kon* ('ghost') in their social labels of PWA (Baker & Djatou 2007). In some places in South Africa today people with albinism are still referred to as '*nkau*', which means 'monkey' (Kromberg, Zwane, & Jenkins1987). Similarly, PWA in Zimbabwe are avoided and feared as the products of witchcraft. Children, mothers and other child care taker, and drunkards tease PWA as "peeled potatoes," "monkeys" and ''ghosts'' (McNeill 1997).

Indigenous myths about albinism in some African societies depict ambivalence about the condition. Perceived ambiguity of this biological condition is evident reference to both blessings and punishments, skills in sorcery and healing, as well as both negative and positive spiritual powers when people talk about human albinism (Kromberg et. al. 2005:911). One popular such a myth as cited by Lund and Gaigher (2002) claims that albinism is a result of witchcraft, sorcery or a curse on both or one of the parents. Myths of this kind suggest that families with babies that have albinism are victims of witchcraft especially within the extended family structure, which leads to the baby being born with peculiar colour and weak skin (Lund & Gaigher 2002: 370). This indicates that lack of knowledge about albinism can lead to many superstitions and social integration issues that affect the well being of PWA. When these aspects are combined with poverty they complicate the problems related to albinism, such as, skin sensitivity to the sun and poor eyesight, which PWA, their families and the society may associate with maneuverings of anti-social agents like malicious witches (Lund, 2001).

Albinism is often stigmatized in African cultures as ominous. PWA are potentially dangerous, and frightening in cultures which associate the condition with curses, portent supernatural power, or witchcraft. Stigma is a special kind of relationship between attributes and stereotypes' (Goffman, 1997: 204). Social identity is based on physical appearance and associated social labels. Social interactions, situations and contacts determine the possibilities for social integration of stigmatized by those who the society perceives as 'normal' (Goffman 1963). This attitude distinguishes between people who are discredited and those who are discreditable. A discredited person is someone who is inferior, or unacceptable qualities are evident on the spot, while a person who is discreditable has undesirable characteristics that are not immediately perceivable to those present.

Goffman (1997) describes three types of stigma: First; abominations of the body, like physical deformities, second; blemishes of individual character, and third; ethnic stigma, referring to race, nationality and religion. A person who is stigmatized is seen as a victim, inferior, and someone who is less human. The dilemma for 'people who are normal' lies in finding a balance between making impossible demands where the stigmatized have inadequacies, and on the other hand, giving these individuals a chance for full social integration and participation. However, Goffman (1997, 1963) talks about normality as a counterpart to stigma, but he does not explain what normality is, or how it is constructed.

Davis (1997), unlike Goffman made an attempt at explaining what normality is and how it is constructed in order to understand the notion of normality and disability. Davis (1997) argues that we live in a world of norms, of average people, where we aim to be normal, or deliberately try to avoid being normal. However, this revolves around culturally normal person or behaviour. In order to understand social integration and livelihood issues among PWA the concepts cultural construction of normality and the normal body are instructive. In this sense the problem is not the albinism, but how the condition constitutes both natural biological exclusion which shapes cultural practices and perspectives that aggravate social exclusion and livelihood insecurity among affected people.

2.3 Bio-cultural Exclusion and Albinism as Disability

Much of the literature about disability portrays the assumption that people with biological inadequacies and physical disabilities necessarily concede to the social labels of weakness or incapability. However persons with albinism often respond to stigmatization, discrimination, and sometimes even mal-treatment from society by withdrawing from normal social life. Albinism in the African cultural ecology is among the stigmatized conditions that are difficult to conceal. According to Jones *et al.* (1984) some marks are indelible or unchangeably noticeable to all that are involved in a relationship while others remain undetectable to some participants.

Persons with albinism experience double exclusion, that is, biological and cultural. Their condition entails unusual biological and social difficulties, which constrain their effective participation in daily social and cultural life as well as livelihood activities. This characterizes bio-cultural challenges entailed in fundamentally two-fold experience of exclusion that African health ecologies may worsen. First, the biological vulnerability of PWA compels them to avoid sunshine and activities that would risk their fragile bodies. Second, stigma related to albinism lead them to shy away from the perceived discomfort of the public curiosity and gaze. Owing to this PWA may resort to withdrawal from daily social spaces. They may seek solitude, which worsens the alienation they experience in their daily lives (Cf. McLeod 2010:19).

Discourse concerning deficiencies of social and physical lives of PWA often result in the generalized association of albinism with disability. Conversely, living with albinism may not necessary entail absolute disability or social and livelihood disadvantage *per se*. Whether albinism amount to outright disability or not is still a debatable issue. In African cultures, however, perspectives on abilities of PWA and victims of other are shaped by social attitudes, cultural values, beliefs and popular myths. These aspects contribute to inadequate understanding, superstitions and prejudice based on the appearance of PWA. However, perennial discrimination, stigma, and inability of governments to recognize albinism as a social and public health problem shape the tendency of PWA to identify with people with disabilities (PWDs). This may be the case despite the fact that albinism traits may not necessarily restrict a person from social existence and performing activities like other average human beings.

Perceived disability related to albinism may fall in the category of culture-bound syndromes (Rebhun 2004). Such conditions entail manifest and tacit psychological symptoms associated with some perceived physical disabilities. This may result in constructions of disability among PWA that would be recognized only within specific culture areas. Baker (2011) notes that in many sub-Saharan Africa superstitions and myths about albinism occur together with the belief that people with albinism are mentally handicapped. Following the misconceptions about human albinism, PWA may be taken to special training and educational institutions, such as, schools for the blind when they not actually experiencing objective disability. Social constructions of disability among PWA characterise subjective and discriminative perspectives on their socioeconomic abilities.

While it is true that African PWA may be disadvantaged due to various situational factors; it is also true that there is a good number them in high socioeconomic strata, as professionals, politicians, musicians among others (McNeil 1997, Hong *et al*. 2006). In addition, empirical observations and literature show that perceived ambiguity of the personhood and disability of PWA vary with cultures. In traditional Indian Hopi culture, for example, albinos have o been viewed over time as any other individuals with congenital defects and have long been well integrated into Hopi society and participated as frequent performers in the elaborate Hopi ceremonies and dances (Woolf &Grant 1962:394). As much as the suffering among PWA may be due to some albinism disability, the society's construction of the disability shape the individual's lived experience of the disability (Michalco, 2002). The bio-cultural perspective of albinism as highlighted in chapter one on the present study helps to understand the social construction of disability, and how cultural assumptions and stereotypes put limitations on the lives PWA and PWDs in general.

Cultures can construct inability where it does not exist *per se*. In addition, the biomedical paradigm, which characterizes western perspectives, is bound to medicalise physical disabilities and transform them into inability or illness. The biomedical paradigm sees disability as something wrong with the biological body and thus constructs disability as a medical problem (Michalco, 2002: 13). The paradox and ambiguity relating to the inability or weakness of PWA is often apparent in the rumours, beliefs and myths associating albinos and their organs with fortune and supernatural influences that can be harnessed to secure prosperity. From the study that Hellum-Braathen & Ingstad (2006) conducted in Malawi, parents of PWA are rarely given adequate explanation of the cause of the condition even by biomedical practitioners. This leaves room for the often non-factual popular beliefs and superstitions about albinism and PWA in sub-Saharan Africa.

2.4 Albinism, Superstitions, power and prosperity beliefs

As aforementioned, belief systems and myths associated with human albinism have far reaching influence on the lives of people with the condition (Baker 2011, Baker et al. 2010), In Eastern, Southern and central Africa as in other part of the continent, these effects present as lifelong challenges to the social lives and livelihoods of PWA. The beliefs and superstitions have always manifested in inaccessibility to education, employment and marriage among the PWA (McNeill 1997). In addition, the persecution, hunting down and killing of PWA in East and Central Africa in the recent past and at present portends the resurgence of the age old African tradition of ritual murder. This refers to the murder involving the removal of body parts from the victims (Roelofse 2012). In this tradition, the killers prefer to extract vital body parts while the casualty is still alive as ritual murder beliefs hold that the 'medicine' made using such organs are more potent than those made of organs harvested from a corpse (Minnaar, Offeringa & Payze, 1992; Mushavhanamadi, 2006).

An upsurge in chain attacks on PWA in Tanzania, Burundi and the wider East African Great Lakes was reported in global media since 2007 as aforesaid (Kiishweko 2008). The practise of 'harvesting' and selling body parts from PWA has apparently been a innovation in the evolving perception of mystical power in the face of economic, health and social uncertainties akin to circumstances of purges of child witches in Senegal (Cimpric 2010). The attacks on PWA, particularly in Tanzania since they began have been linked to the beliefs that the body parts of PWA confer luck, health and prosperity (Baker 2011).

The reports about persecution and killing of PWA in Tanzania and other parts of East Africa today are indicative of the deep-seated African cultural beliefs that body organs, particularly from people with certain physical characteristics, bring into play supernatural power that can transform or alter the cause of some daily life events. In African belief systems and thought, such power can either reduce or augment the vital force of human being, thereby affecting their wellbeing positively or negatively.

Local, regional and international media highlight ways in which victims among PWA were trapped, mutilated, and their organs and body parts harvested and sold to witchdoctors (cf. Baker 2011).

Reports about bodies of people with albinism being exhumed from their graves in Tanzania in order to steal their body parts became very common since 2007. By the end of 2010, over 73 killings of PWA had been reported and filed by Tanzanian police. Cases of PWA losing limbs have persisted today despite attempts to surmount the brutality against PWA. In May 2008, a woman with albinism was killed in Kenya, a Kenyan man was arrested in Tanzania for attempting to traffic a fellow Kenyan for ritual killing. Outrageous cases involving PWA in East Africa have continued to be highlighted by the media and human rights activists to date. As an example, the head of a child with albinism was discovered in the suitcase of a man crossing the Congo border in 2009 (Baker 2011), and an 18 year old man with albinism escaped Benin in 2009 dreading being potential targets of ritual killing (Cimpric 2010).

Beliefs relating to potency of organs from the bodies of PWA often intertwine with beliefs in witchcraft, magic, sorcery and practices intended to manipulate the courses of (mis)fortune (Mesaki, 1993, Stewart &Strathern 2004, Ralushai et al. 1996). The idea that witches steal people's organs and use them for curative (and negative) medicine today are not new as it is part of the traditional repertoire of notions about the powers of the body and powers over the body, in Africa and elsewhere (cf. Stewart &Strathern 2004:86, Green, 2003). However, rumours about international n stolen body organ trafficking, illicit trade in and organ donation complicate the discourse on body organ trafficking and disappearance of victims, including PWA (cf. Green 2003: 73, Baker 1941). In this regard, unspoken suspicion abound regarding the complex nature of cartels involved in the persecution, disappearance and killing of persons with albinism in East Africa and other parts of the continent.

Harassment and killing of PWA in Africa has two dimensions. First, there is the often unspoken 'mysterious disappearance' (Stewart &Strathern 2004). This also relates to the unpublicized killing by suffocation or other culturally sanctioned mechanisms, which characterises extermination of children with albinism at birth. The second aspect is manifested in the reported cases of killing or attempted murder of adult PWA, who survive the life threatening onslaughts at birth. People in traditional African cultures associate albinism with bad omen, misdeed in the lineage and even shame. Consequently, an infant with albinism would be killed to avoid the stigma. Among the Shona of Southern Africa, a mother who gives birth to an albino child often fear the stigma related to notions of having slept with the *tokolosh,* evil spirit, a white man, the consequence of either having angered spirits by witchcraft and sorcery or mystically having sexual relation with them (Bourdillon 1987, 149, Baker *et. al* 2010:172, Murphy *et.al.* 1988).

Discrimination, killing and fragility of livelihood of PWA in East Africa are to a large extent a function of witchcraft and condescending beliefs and superstitions. Tanzania carries the largest number cases of killings and persecution of PWA ever reported in East Africa. Tanzania and many other countries in Eastern Africa are still largely characterized by traditional superstitions and beliefs relating to witchcraft, sorcery and the potency of different sources of power for therapeutic and fortune-seeking activities. This is part of the ever growing scenario of religious and therapeutic pluralism and syncretism in East Africa. The highest incidence of killing and persecution of PWA in Tanzania has been reported in Mwanza, Shinyanga and

Mara where Christianity, Islam, Independent Christian sects and traditional African religion characterise the context of health-seeking and livelihood struggles (Tamric Agency, 2000).

Rationalizations for maltreatment of PWA are often embedded in both venerable superstitions and traditional belief systems in Eastern Africa. This coincides with the stark reality of lucrative but obscure trade in body parts from PWA. The PWA are the most targeted of all the other victims of obscurantism, which promises to use body parts and other forms of magico-religious rituals to alter poor people's fragile livelihood and provide synergy in the search for more power among those who are already politically and economically well to do (cf Dave-Odigie 2010:71, Magram, 2009).The Tanzanian government publicly condemns the practice of killing and mutilating its PWAs, and has put in place mechanisms to protect the population affected by albinism; yet the measures are still inadequate and ineffective (Larson 2011). Tanzanian PWA have lived in increasing sense of fear, abandonment and despair. Media reports have indicated that other African countries, Burundi and Democratic Republic of Congo have had similar occurrences of killings of PWA. The buyers of albino body parts are difficult to understand but popular narratives characterize them as either the rich merchants or the politicians. However, the Republic of Burundi does not appear to be afflicted with the same kind of judicial apathy. While the trials in Tanzania were completely stalled in the year 2012, 9 people in Burundi were convicted for the murders of PWA. All the nine killers in Burundi were sentenced to jail terms ranging between 12 to 30 years, with one of them serving a life sentence (media@underthesamesun.com, accessed on 4th April 2011).

2.5 Status of Human Rights among PWA

Many studies, reports and literature on the plight of people with albinism overemphasize socio-cultural etiology at the expense of other equally significant issues. Different dimensions of livelihood and human rights issues are obscured in the lip service of attributing all the discrimination and persecution of PWA to traditional beliefs. Contrary to what many people emphasize, the suffering depicts livelihood vulnerability of both the victims and the offenders. Human albinism therefore entails livelihood, economic factors, human rights issues and political dimensions for all the ‘normal’ citizens and those affected with the condition. TAKNET; Tanzania Knowledge Network (2009) policy brief aptly points to the way in which superstitions and beliefs should be considered as products of wider social, economic and political circumstances. The policy brief acknowledge the link between superstitions and people’s economic status.

Arguably people facing economic hardship are more compelled to engage in activities and embrace beliefs that may infringe on other people’s rights while they attempt to cope with widespread livelihood fragility and insecurity. This may explain propensity to inhuman and non-sociable practices and credulity in relation to magico-religious experiments for luck and material prosperity. Increasing poverty and widening economic gap partly explain the practices associated with witchcraft and their concomitant effects of livelihood of PWA. However, the sale of African people with albinism by Africans is not a recent phenomenon.

Mid eighteenth century naturalists and thinkers held that PWA had a pariah status as some of them found to have other unique biological traits, such as the midget-sized albino man that Voltaire had seen in 1744 (cf. Curran 2011:144). Albinos were considered a very small and a very rare nation living in the interior (middle) of Africa, among the darker people of the world (Curran 2009). Reports on albinos at this time characterized them as having minimal strength, a trait that confined them to caves. Notable in Curran's (2011) analysis is the observation that fellow negroes (black people) hunted down and captured PWA from time to time and would hand them to western travelers and ethnologists who bought the African albinos for curiosity's sake (Curran 2011:144). In the 1750s, most naturalists agreed that the albino was the diseased or degenerate product of black parents. Many naturalists and social philosophers during this time also speculated about the causes of albinism. The speculations included improperly stimulated maternal imagination, leprosy, small pox or miscegenation.

Beliefs concerning albinos reflect a misunderstanding of albinism within the great "black"/"white" ethnic divide that characterize its pervasive existence in colonial post-colonial Africa. However, very little ethnographic attention has been given to albinism and albinos, as well as their often terrible fate in Africa. While there is some literature on the predicament of PWA in Southern Africa, for example, the ethnologists tended to indicate the capacity of PWA to mysteriously operate symbolic meditation (cf Pina-Cabral, 2002:5). It is clear that the plight of PWA goes beyond their biological condition—albinism – to include socio-cultural responses to it.

The *ethnography of albinism* as opposed to *ethnography of the albino* proposed in this study is a plea for empathizing with the plight of PWA in their wider contexts. Tanzania Knowledge Network (2009) pointed to the reality of the fact that killing of PWA reflect attempts to cope with livelihood insecurity. Similarly both government officials and social commentators in the country and beyond have recognized the complex relationship among lack of knowledge, injustice, traditional beliefs, superstitions, poverty and the wave of killings targeting PWA in Tanzania.

The quest for money and economic livelihood explain the reported cases of trafficking to Tanzania from countries in the larger Eastern Africa and Great Lakes region. Poverty in general correlates with levels of crime and wickedness, which are linked to increasing gap between the rich and the poor with consequences for livelihood PWA. Poverty is one of the underlying factor in witchcraft accusations and its negative effects in many African societies. Like witchcraft accusations against children in sub-Saharan Africa, witchcraft activities that affect PWA can be linked to multiple social, economic (livelihood security) and political factors (Anguilar 2006, Erickson 2012, TAKNET 2009, Miguel 2005). Popular narratives in Tanzania indicate that the killings of PWA escalate during political election times as demand (Makulilo 2011) increases for magical portions by politicians seeking election or re-election.

Available literature, media reports and the foregoing review further affirm that the persistence of marginalization, discrimination, persecution and killing of PWA in Tanzania and the rest of Africa demonstrate inadequate social and political will to deal with the problem. While the governments may condemn the vice, little is done to find durable solutions. According to Miguel (2005: 1170) many politicians are reluctant to move against those who murder witches among the Sukuma people of Western and Southern Tanzania, since doing so may open them up personally to witchcraft and other accusations. This may explain perceived inaction regarding killing of PWA. It demonstrated unequal power that shape livelihood insecurity among majority of the people in developing countries. An extreme form of rationalization of killings related to witchcraft may be linked to perception of such acts contributing to the welfare of society. People with albinism in Tanzania as in other parts of Africa are victims of violation of human rights in many ways. Economic in inequality deprive the general public, including PWA the fulfillment of their basic needs. This determines the efficacy of individual and institutional mechanisms of coping with livelihood shocks among persons with and without albinism.

Killings and discrimination on the basis of perceived biological abnormality is against both Tanzanian law and international human rights norms (Miguel 2005). The experiences of PWA in the framework of human rights violation may be twofold. First, albinism creates varied levels of perceived or absolute disability. This contributes to inadequate enjoyment of human rights and fundamental freedoms by PWA in the political, economic, social, and cultural or any other field of public life as other citizens (UN General Assembly 1965). Ambiguity and general ignorance surrounding albinism may cause gross violations of human rights in both the public and private spheres. These prevent access to resources and perpetuate a state of neglect and abuse among PWA (cf Allen 2010: 18). Secondly, PWA constitutes a social, cultural and even ethnic minority, which may be denied equal human rights as other members of the society. A minority in this sense is as a group numerically inferior to the rest of the population of a state. The minority groups occupy a non-dominant position. Members of the minority group may be nationals of the state, but possess ethnic, religious or linguistic characteristics differing from those of the rest of the population and show, if only implicitly, a sense of solidarity, directed towards preserving their culture, traditions, religions or language (Jayawickrama 2002: 844). In summary, beliefs, attitudes and superstitions about human albinism interact with other factors in influencing human rights and experience of livelihood vulnerability. The present study therefore set out to characterize the bio-cultural perspectives on human albinism. It demonstrated the implication of ensuing scenario for social inclusion policy of PWA in East Africa, drawing on experiences from Tanzania.

CHAPTER THREE

Methodology

3.1 Introduction

This study was spread over the period between March 1st 2011--when it was conceptualized—and March 2012; the time the fieldwork was authorized by Tanzania Commission for Science and Technology (COSTECH). The main fieldwork by the principal and co-investigator was limited to visits in Tanzania in April, July, and October 2011 owing to financial constraints to longitudinal ethnography. The study used the case of Tanzania to explore the social, cultural and political contexts of the livelihood struggles among people with albinism in East Africa. This chapter explains the methodology that was used in the study and its justification. In this regard, the chapter presents the research design, site selection and description, study population, sample size and sampling procedures, methods of data collection and analysis, limitations to the study and ethical considerations. The research strategy and approach in this study is a plea for 'ethnography of albinism.

3.2 Research Design

The hallmark of this study is its ethnographic design. This essentially entailed a rapid ethnography of albinism in Africa drawing on the record of daily life experiences people with albinism (PWA), their kin and social networks in Tanzania. The ethnography incorporates perspectives of all stakeholders interested in the welfare of victims of albinism, including the PWA themselves as a socio-cultural minority in Tanzania. The design of the present study—ethnography of albinism-- is different from the classical 'ethnography of the albino' (cf. Curran 2011). Ethnography of the albino was driven by curiosity about 'white negroes' in the heart of black Africa in order to determine the degree to which PWA constituted an independent category from the rest of humanity. This classical attempt at ethnographic work on albinos was based on an assumption that PWA constitutes a 'racial category' beyond the Western world that warranted ethnological study. However, it has long been established that albinism is a condition that affect all humanity and other species at all times and in all places of the world. Therefore, ethnography of albinism design is proposed in this study as an approach that can facilitate the characterization of the variation in perspectives on albinism and experiences of PWA, relative to socio-cultural and historical, political and economic circumstances. The main focus of this approach is to include the perspectives of all actors concerned with the rights and well being of persons affected by albinism; including PWA themselves.

Ethnography of albinism design is a plea against the study of PWA as necessarily a weak and vulnerable Africa human category *per se*. This may contribute to the misrepresentation, mistranslation and even over representation of the experiences of PWA. We content that ethnography of the albino may contribute to violation of the rights of PWA, presenting them as racial freaks in media and ethnographic reports, for instance. The ethnographic design in the present study entailed the use of multiple qualitative strategies to explore the experiences of PWA and aspects of their vulnerability in the wider socioeconomic context of citizenship and social exclusion in Tanzania.

The ethnographic design was most suitable for eliciting qualitative on social interactions involving PWA. The focus of this study was on understanding social scenes, emotional expressions, shared beliefs, practices artifacts, folk knowledge and cultural action. Therefore ethnography could easily blend with minimal descriptive survey techniques to explore and represent emic views about albinism and the plight of people and families affected by albinism. Media reports and literature review presented in chapter two provided an opportunity for rapid comparative ethnography of albinism in Africa and other parts of the world.

3.3.0: The Macro-ethnography site: Tanzania

The ethnography was carried out in the united republic of Tanzania as aforementioned. This East African country is situated along the Indian Ocean. Kenya and Uganda share borders with Tanzania to the north, and Burundi, Rwanda and Congo to the West (see figure 1). Mozambique, Zambia and Malawi are located to the South of the country. Tanzania is part of the ethnographic and population zone contributing to the high prevalence of human albinism in Africa relative to the global average. Persons with albinism constitute about 1 in every 4,000 people in South Africa and possibly 1in 5,000 in Nigeria (Lapidos 2009). The prevalence of human albinism in Tanzania has been estimated at 1 in 1,400, that is, about 30, 000 PWA, but complete and accurate census is yet to be concluded (Hong *et al*. 2006).

They high prevalence of PWA in Tanzania relative to other African countries is mystifying. Various hypotheses may attempt to account for this incompressible higher number of PWA in Tanzania. This could be attributed to higher chances of survival resulting from increased observance of the right to life of children and youth with albinism as aforementioned. On the other hand albinism may be more ubiquitous in some geographic areas due to inbreeding. According to Kromberg and Jenkins (1982) albinism is less prevalent the South African Zulu and Xhosa (1 in 4,500) than the Swazi and Sotho-Tswana ethnic groups (1in 2,000), due to stronger and wider range of incest taboo. The same hypothesis is applicable in Zimbabwe where only 4/5 PWA are of the Shona group which has stronger incest taboos, too.

According to the 2012 the population census in Tanzania, of thee estimated 44,928,923 million, at least 200,000 people were thought to have albinism. Tanzania is predominantly a rural peasant economy with high rates of illiteracy and poverty. The country is characterised by religious syncretism with people borrowing eclectically from Christian, Muslim and traditional belief systems. The local people resort to traditional religious beliefs and superstitions and modern Christian and Islamic religious practices either sequentially or simultaneously as ways of coping with livelihood adversities or insecurity.

Traditional healers renowned for their healing, divination and sorcery skills prescribe and sell the charms, and the albino murder victims (Bryceson, Jønsson & Sherrington, 2010).Tanzania became the focal point of reports about killings of PWA and their persecution since 2007 as indicated in chapter one and two. Many of the brutal episodes involving trafficking body parts in the neighbouring countries (figure 1) in the last one decade or so were somewhat associated with the obscure activities in Tanzania, which affected the lives and wellbeing of PWA. Tanzania was therefore an appropriate site for this study and exploration of issues in the socio-cultural lives of albinism and PWA in East Africa. The actual ethnographic fieldwork was conducted in three regions of Tanzania; Mwanza, Dar es salaam and Mtwara (See figure 1).

These research sites were selected purposively owing to the research theme and perceived regional distribution of exclusion and persecution of PWA in Tanzania.

3.3.1 Mwanza albinism ethnography site

Mwanza region (Figure 1) has the largest reported number of killings of PWA in Tanzania since the peak of the problem's resurgence in 2007. This region has the highest number of traditional healers whose activities include resort to mystical powers to heal, protect against witchcraft and sorcery and ensure material prosperity.

Areas with most frequent media reports about the tribulations of albinos and their families owing to cultural beliefs and practices that threaten their social and economic survival were purposively selected and included in the study frame. The spate of killings and mutilation of PWA in Mwanza region has central in the discourse of human albinism, which has contributed significantly in putting Tanzania and East Africa on the ethnographic map regarding societal responses to albinism.

The location of Mwanza region on the shores of Lake Victoria makes it easier to describe the prevalence of tribulations of PWA to be more in *eneo la ziwa* (the Swahili equivalent of 'Lake Zone'). The main ethnic groups in this region are the Sukuma (90% of the population), Zinza, Haya, Nyamwezi Luo, Kuria, Jita and Kerewe (The United Republic of Tanzania 1997a). Available literature indicates that the Sukuma are most likely to be involved in traditional healing, quest for material prosperity especially luck in gold mining, and witchcraft beliefs and practices that affect people with albinism (Durand 2010).

Figure 3.1: Ethnographer with PWA and his parents in Mtwara

Figure 1: Map Tanzania: International boundaries and the study sites

Source: Adapted from: http://www.sitatungasafari.com/tanzania/images/map.png March 24, 2014

Most of Mwanza region is dry land (57%) with upto 43% of the region being wetland, of which the surface area is under water (United Republic of Tanzania 1997a). The agricultural productivity of the area is very poor, with most of the people in the area eking livelihood from economically insecure fishing, mining, subsistence and pastoralist activities.

Mwanza region is strategically located in relation to circulation of activities that contribute to violation of human rights of PWA in a wider area of Eastern Africa. Mwanza is bordered by Kagera district to the West, Shinyanga district to the south and South West, and Mara region to the north-east. Both the neighboring districts and region are part of the wider spatial scope and catchment of Mwanza in the Tanzanian narratives on PWA. The northern part of Mwanza is surrounded by the water of Lake Victoria with strategic link to Uganda and Kenya with regard to recent media reports based on community rumor and observations on circulation or trafficking of (albino) body parts and magical practices. Arguably, the proximity of Mwanza to Burundi and Rwanda would further define the wider culture area or culture map in the ethnography of albinism in East Africa.

3.1.2 Mtwara Albinism Ethnography Site

Mtwara is one of the 20 administrative regions of Tanzania Mainland, to the extreme southern part. It lies between longitudes 38 degrees and 40 degrees 30" east of Greenwich, and between latitudes 10 degrees 05" and 11 degrees 25" south of the Equator (United Republic of Tanzania 1997b). To the north and east of Mtwara is Lindi region and the Indian Ocean respectively. River Ruvuma separates Mtwara from the Republic of Mozambique to the South. In this study, Mtwara constitutes a geographical, historical and cultural continuum zone that link the ethnography of albinism in Tanzania (and East Africa in general) to the wider ethnographic context in Southern Africa. This region constitutes the culture area continuum that blends into the ethnography of albinism in Tanzania.

The indigenous people of Mtwara region are mainly of Bantu origin. The most dominant group is the Makonde of Newala, Tandahimba, Masasi and Mtwara rural, which comprise 60% of the population (United Republic if Tanzania 1997b). This group is followed by the Makua of Masasi and Mtwara rural, and the Yao, the third group, are found in Masasi. The ethnic groups in Mtwara, especially the Yao and Makua are also found in Mozambique and Malawi. This implies that the ethnography of albinism in Tanzania and these Southern Africa countries is highly likely to have some similar patterns, and that these countries are possible catchments for albino related activities Tanzania. As indicated in chapter two, PWA in Tanzania are subjected to horrific discrimination. However, in Mozambique and Malawi, parents and relatives often abandon persons with albinism from child birth. In view of the cultural continuum of bio-cultural exclusion of PWA in Mozambique, Malawi and other culture areas in Southern Africa may manifest similar essential characteristics with those the PWA in Tanzania and the rest of East Africa experience. The proximity of Mtwara to Mozambique gives a glimpse into the wider socio-cultural continuities of the ethnography of albinism in Eastern and Southern Africa.

The essential rationale for the inclusion of Mtwara ethnographic site in the present ethnography of albinism in East Africa is that the region is relatively isolated from the main center of persecutions of PWA in Tanzania, especially the Lake region. The Mtwara ethnographic site was intended to help in finding out variations and similarities in the beliefs about albinism and experiences of PWA in Tanzania. Second, media reports on violations of PWA rights were rife in the region prior to and during the fieldwork. Thus Mtwara would provide a chance to interact with and illicit information from a study population that was not directly victimized due to albinism. Mtwara inadvertently has a large community of PWA in Tanzania, apart from those found in Mwanza. The PWA in Mtwara equally mobilized by the Tanzania Albino Association (TAS) popularly known as *Chama cha Albino cha Tanzania*, in Kiswahili language, to pursue their rights and social inclusion.

3.1.2 Dar es Salaam Ethnography site

Dar es Salaam region is situated along the Western Coast of Indian Ocean between 6 and 7 degrees South of the Equator and between longitudes 33.33 and 39 degrees East of Greenwich. The City experiences a modified type of equatorial climate. It is generally hot and humid with average temperature of 29ºC throughout the year. The Coast Region is to the North, West and South of Dar es Salaam while the Indian Ocean is to the East.

Dar es Salaam city was originally dominated by Zaramo and a few other ethnic groups, particularly the Ndengereko, and Kwere (originally believed to have come from Mozambique). However, due to urbanization many people from different ethnic origins have immigrated to the city in big numbers. This has contributed to a continuous process of cultural change (Dar es Salaam City Council 2004). The Zaramo; the predominant ethnic group are entirely Muslim. Like Christians in Dar es Salaam and elsewhere the Zaramo practice religious syncretism; blending Islamic beliefs with traditional African Belief Systems and superstitions.

The productive sectors in the region include agriculture, livestock, fisheries, forestry, cooperatives, tourism, yet most of the population in the region lives below poverty line (United Republic of Tanzania 2010). However, the city and the entire region of Dar es Salaam experience livelihood insecurity due to poor socio-economic and environmental conditions caused by low economic growth of 4% annually. General poverty, inadequate social services exacerbate the poor livelihood situation, which is further, manifested growth and persistence of slums, criminality, violence and youth delinquency. Daily livelihood struggle shapes general jealousy and fatalistic attitudes, and desperation in Dar es Salaam. These aspects are visible in reports on vices such as violence, alcoholism, drug abuse commercial sex, mugging, and banditry. As in other East African cities, Dar es Salaam epitomizes social inequality, unequal accessibility to basic social services and lack of adequate incomes City council of Dar es Salaam, 2010). Consequently, Dar es Salaam depicts typical cases of social exclusion, mistrust and intolerance in social interactions, especially during peaks of political activity. High rates of unemployment or marginalization, illiteracy and inadequate family care contribute further to social inequalities.

While this ethnography was to be conducted in the purposively selected Mwanza and Mtwara regions, it was inevitable to include a couple of sites in Dar es Salaam. As part of the formal research authorization process in the capital city of Tanzania, the principal investigator was granted short residence permit in Dar es Salaam. This was handy for general observation and informal conversations about the subject of human albinism with a wider audience. Key ethnographic sites in Dar es Salaam included Ocean Road Cancer Institute, which housed the Tanzania Albino Society (TAS). The other site was Mikocheni B sub-region where Under The Same Sun (UTTS), an International Non Governmental organization advocating for the rights of PWA is situated. Under The Same Sun (UTSS) Fund is a Canadian, Christian charity founded in 2008 by Mr. Peter Ash. UTSS is investing significantly within Tanzania to improve the lives of Persons with Albinism (PWA). The primary focus of UTTS is on advocacy and education as well as assisting PWA to access external information, education bursaries, health care and other community supports to assist with their genetic condition http://www.underthesamesun.com/, accessed on March 31, 2014).

3.2.0 Study population

This ethnography set out to include Persons with Albinism, their family members and care givers, and community members in the abovementioned ethnographic sites as much as possible. The study was also to include other actors involved in initiatives to secure livelihood, human rights and general wellbeing of PWA. The other actors included officials working with the Association for people with disabilities in Tanzania, Tanzania Albino Society (TAS) and Under The Same Sun (UTTS).

3.2.1 Macro- and Micro-ethnographic site selection.

As indicated earlier in this chapter and in chapter one, Tanzania, the macro ethnographic site was purposively selected. The fact that Tanzania dominated local and international reports about persecution and social exclusion of PWA in East Africa was puzzling and intriguing at the time this ethnography was being formulated. Previous research figures suggest that there are 370,000 albinos in Tanzania, far higher than in any East African country (Onyango-Obbo, Daily Nation; November 28, 2008). Researchers have further suggested that the source of the albino gene can be traced to Africa's east coast with a higher reservoir perceived to be in Tanzania. The media had reported the most heinous cases involving albinos in the previous five years in East Africa until the time of the study (2011/2012) occurred in selected localities in Tanzania.

Mwanza region (Lake Victoria region), Southern Tanzania Region (Mtwara, Masasi and Mikindani Districts) and the city of Dar es Salaam (and its environs, especially Mikocheni B, Kwa Warioba and Ocean Road Cancer Institute were purposively identified and selected as the main sub-sites for the study. Based on media reports on the high number of killings of PWA, arrests of suspects and concentration of traditional healers, Mwanza region was predominantly selected as a suitable target area for this study. The main points of reference were various villages in Magu and Misungwi districts.

Mtwara; the coastal Southernmost region of Tanzania, although considerably presumed a low risk area for albino killings and attacks also featured in reports of persecution of PWA. This region was also purposively sampled to facilitate ethnography on perceptions and level of anxiety among PWA living far away from the most active region-Mwanza--associated with more intense tribulations of PWA Some of the questions the study sort to respond to in this coastal region were; what was the extent of daily life phobia of being attacked? How did they perceive killings and murder of their colleagues in the northern and Lake Regions?

The main sub-sites that were purposively sampled in Mtwara Region included Mtwara/Mikindani District. This encompassed the area around Mtwara urban, peri-urban, and rural areas. The ethnographer visited particular areas to observe the daily life ad livelihood experience of PWA. The particular areas selected purposively and visited in Mtwara/Mikindani were: Maduka Makubwa/Raha Leo, Magomeni, Majengo, Mgenga, vigaeni, Kitera, Kisutu Village, Mikindani and Kitere. Mtwara/Mikindani District covers an area of 163 square kilometers and has 2 administrative divisions 13 wards and 6 villages (United Republic of Tanzania 1997a).

In addition, ethnographic fieldwork extended to Masasi; the largest district in Mtwara, which is about 200 kilometers from Mtwara town. It covers 8, 940 square kilometers with the largest number of divisions (7), wards (30) and villages (214); which account for its 55 times the size of the urban Mtwara/Mikindani district(United Republic of Tanzania 1997a). The purposively sampled areas for the ethnography in Masasi were Masasi town, Gida, and Mkarapa. Snowball sampling supplemented purposive, accidental and judgmental sampling of participants throughout the study and in all the ethnographic sites. These non-probability sampling techniques facilitated tracing PWA and their families through the help of the officials of TAS and the Tanzania Organization of People with Disabilities.

3.2.2 Sampling Participants: Mwanza Region

In Magu, eight (8) people with albinism, 3 females aged between 16 to 23 and five (5) males aged between 17 and 36, and their parents participated in the study. At the same time, insights from key informants drawn from different departments such as: - social welfare services, community and public health, Security, Youth and children, education, religious and traditional healers were intensively involved 3 Focus Group Discussions (FGDs). In Magu district alone, a total of 24 purposively selected respondents (8 with albinism and 18 without the condition) participated. Out of these number, 1 female and 2 male traditional healer, (commonly known as Waganga) in Kiswahili) were among the key informants.

In Misungwi district, a primary school; Shule ya Msingi – Mitindo, provides refuge to about 37 pupils with albinism. The pupils boarded in the school among over 600 children with normal pigmentation who did not board. 5 pupils with albinism and 3 of their teachers participated in the study. Two (2) officials of Chama cha Walemavu wa ngozi – Mwanza, and 4 members of Shirika la Vyama vya walemavu Tanzania (SHIVYAWATA), An association of all the groups of people with disabilities in the country – Mwanza region contributed to the discussions. A FGD of six (6) students, where 2 had albinism (previously from Shule ya Msingi - Mitindo in Misungwi) who were studying in St. Augustine University of Tanzania (SAUT) – Mwanza, participated in a focus group discussion. Table 1 is a summary of the distribution of study participants in Mwanza.

Table 1: Distribution of study participants in Mwanza

Participants	Mwanza		Total Respondents
	Magu	Misungwi	
PWA	8	9	17
Without albinism	18	15	33
Total	**26**	**24**	**50**

Religious leaders in Igoma Catholic mission - Mwanza which provides protective materials, huts and sun screen lotions to people with albinism and the a priest in Bujora parish were part of the key informants. A pastor in the Assemblies of God – Mwanza and Four (4) officials from the ministries of primary education, children's department, people with disabilities and security departments were among key opinion leaders. In Misungwi district nine (9) people with albinism and 15 other stakeholders were involved in the study.

3.2.3 Study Participant Sampling: Mtwara Region

All the participants in the study in Mtwara region were selected by purposive, accidental and convenience sampling. Officials of the Tanznia Albino Society at the Mtwara Head quarters estimated the number of PWA in Mtwara Mikindani to be 19. Those who were reached included 14 PWA, among them, 2 primary school boys, 1 secondary school girl, 1 woman and 15 men. Other participants without albinism included those who participated in of the Focus Group Discussions (FGDs) and In-depth interviews and conversations (both formal and informal). The study participants in Mtwara included 15 more Key informants; 2 selected from St. Augustine University of Tanzania (SAUT), 6 from the Association of Organizations for People with Disabilities and 7 members of the local leadership, including village elders/chairpersons. This totaled to 35 people without albinism, among them family members and caretakers. 20 of these participants were male while 15 were female with an age range of between 15 and 70. One traditional healer (*mganga*) participated in the study in Mtwara/Mikindani urban, peri-urban and rural areas. Table 2 below presents a summary of the study participants selected by purposive, snow ball and convenience sampling in Mtwara/Mikindani and Masasi.

Fewer participants were recruited in Masasi owing to distance and time constraints. The participants included those who took part in two FGDs at different locations. 4 PWA; 2 male, (41 and 19 years of age), and 2 female (25 and 20 years of age) participated in the study in Masasi. The two FGDs comprised 8 and 7 participants, respectively. A total of 19 people participated in the study in Masasi region as summarized in table 2 below.

Table 2: Distribution of study participants in Mtwara

Participants	**Mtwara**		**Total Respondents**
	Mtwara/ Mikindani	**Masasi**	
PWA	20	4	23
Without albinism	51	15	66
Total	**71**	**19**	**90**

3.2.3. Sampling of Participants: Dar es Salaam

In Dar es Salaam, purposive, convenience and accidental sampling were used during the first visit in April 2011 and the return visit in October 2011. There were two points of ethnographic interaction in Dar es Salaam; the Tanzania Albino Society (TAS) headquarters, and at Ocean Road Cancer Institute), and at the Under the Same Sun (UTTS) national offices in Mikocheni ‘B’.

The interaction at Ocean Road Cancer Institute involved PWA who came in and out of the TAS office for various forms of assistance, including asking about sun screen cream. More specifically conversations were held by 3 PWA at TAS, Ocean Road Cancer Institute, 4 officials of TAS and 2 officials at the UTTS headquarters (See table 3).

Table 2: Distribution of study participants in Dar es Salaam

Participants	**Dar es Salaam**		**Total Respondents**
	Ocean Road Cancer Institute--TAS	**Mikocheni 'B'-UTTS**	
PWA	7	2	9
Without albinism	--	--	--
Total	**7**	**2**	**9**

A total of 9 PWA were interviewed in Dar es Salaam, bringing the number of PWA who directly participated in the present study to 49. However, non-participant observation involving more actors among the PWA and other participants took place throughout the study. The study entailed the use of various qualitative data collection instruments.

3.3 Data Collection Instruments

This study relied on semi-structured interview schedules and Focus Group Discussion (FGD) guide. Individual, key informants and focus group discussion guides were also extensively used for systematic elicitation of information from various respondents and informants (see appendices I-1V). Use of the standard data collection instruments entailed instant translation in Kiswahili language by the principal and co-investigator with the help of local field assistants. After initial conversations and interviews, the researchers, who are also competent in Kiswahili, had mastered the pattern of obtaining the semantic equivalents of the instruments prepared in English.

All the interviews were conducted in Kiswahili language as all the local people in Tanzania are more comfortable speaking the language. Minimum translations and interpreter mediations were required in this study. As aforementioned, both the principal ethnographer and co-investigator are versed in Kiswahili; their national language. Tape recorders, video cameras and photo cameras were used with respondents consent to capture images and information from in-depth discussion sessions.

3.4 Data Collection Methods

In-depth discussions and life histories of PWA and their families guided cyclic ethnographic data collection. We recorded verbatim narratives from multiple actors in the discourse on albinism in Tanzania. Using observational skills daily life experiences of PWA and members of their social networks were also recorded. Participant and structured non-participant observation was used to note the living conditions and other health-related experiences of the PWA.

A series of focus group discussions (FGDs) with PWA, their family members and other care givers were conducted to elicit their shared experiences. Additionally, this study relied on unfocussed informal group and individual conversations on the perceptions, attitudes, beliefs and superstition regarding PWA and their livelihood struggles. This ethnographic design encouraged methodological flexibility, which facilitated collection of information through informal and standardized conversations with key informants and other members of the community.

In Mtwara, the ethnography involved discussions and conversations whenever PWA were found. Informal conversations were conducted in market places, in schools and in homes. Home visit gave the opportunity to observe the living environments of PWA and their families. We were also able to observe interactions between PWA and other people in their communities and natural social settings.

Key informants included policy makers concerned with integration of albinos as a cultural minority group in East Africa. We included convenient samples of officials in institutions dealing with the plight of albinos, such as the Tanzania Albino Society (TAS [see figure 3.2]), Tanzania Association of People with Disabilities (TAPD) and the Ministry of Culture and Social Services. Non Governmental Organizations such as Under The Same Sun (UTSS) were widely consulted. Non-obtrusive rapid assessment informal conversations were conducted. The study took advantage of the methodological flexibility of ethnography to elicit more information and cross-check themes and cultural domains from the general public through informal conversations.

The principle of data saturation determined the number of key informants and the length of time taken to elicit information on particular themes and issues from different respondents and key informants. In addition, this study enlisted the use of informal conversations with varying degree of continuous focus on relevant themes. Revisiting issues that came up in previous interviews and conversations was adopted as a way of cross-checking, clarifying and getting more information. Return visits to families facilitate more conversations with relatives to PWA for further insight into issues in the lives of PWA and their relatives.

3.4 Data processing and Analysis

The qualitative data and narratives were recorded in field notebooks. Voice recorders were also used to get the natural flow of the narratives. The data was transcribed verbatim and edited for clarity and jettisoning superfluous details. The data were then organized, and analyzed in view of themes reflected in the study questions and objectives outlined in chapter one. The main themes are summarized interpreted and presented in chapter four.

Data processing and analysis were conducted in consideration of the secondary data elicited in the literature review presented in chapter two. This facilitated rapid comparative ethnography of albinism. This entailed reference to existing data and narratives relative to new fieldwork data collected in the ethnographic sites in this study. We began the study by literature search of a wide array of information on 'ethnography of albinism. This study analyzed cross-cultural perspectives on disability, social exclusion, and human albinism since its inception and the write-up stages.

This facilitated identification of gaps in the knowledge about the experience of albinism as culturally constructed. Ethnographic pre-analysis during data collection & final analysis was undertaken. Processing, coding and analysis using the Maximum Qualitative Data Analysis (MAXQDA) computer programme. Identification of recurrent themes in verbatim reports; domain analysis aspects such as local stigma labels, prejudicial references and cultural maxims were also considered. Video, voice recording and photograph reviews were done for participant self-reflexive and intersubjective inputs.

The preliminary findings were presented in a debriefing/ dissemination session organized by the department of research at the Catholic University of Eastern Africa. This contributed to the continuous process of analysis that characterize ethnographic studies of this type.

3.5 Presentation of Findings

The study findings are presented qualitatively in the next chapter. Direct verbatim expressions and respondents narratives are presented to emphasize particular themes. The presentation pays attention to the emic perspectives of albinism and its consequences in the wider socio-economic, cultural and political context of Tanzania. An attempt has been made to provide insights into the human, social and cultural organizations associated with the wellbeing of PWA. The findings have been presented as synthesized field notes, drawing on theoretical foundation highlighted in chapter one. The data presentation vacillates between the ethnographic present and past in order to communicate and emphasize the thrust of the findings more appropriately.

3.6.0 Ethical Considerations

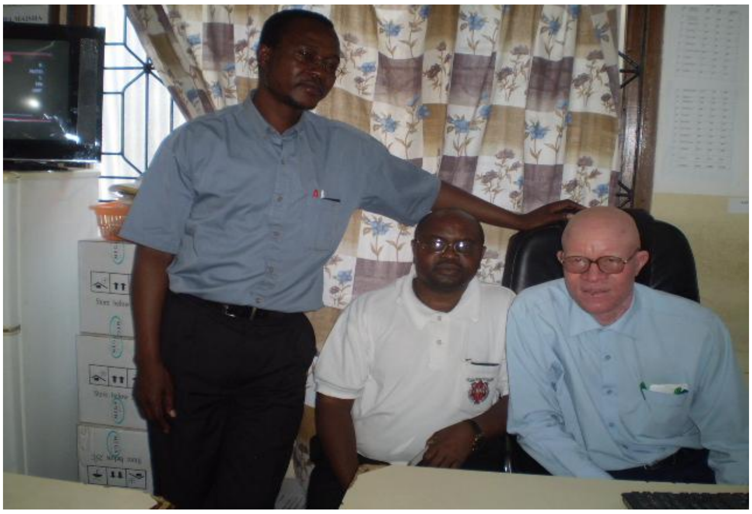
This study went through the due process of ethical approval and clearance by the authorities in Tanzania. We applied for clearance through the Tanzania Commission for Science and Technology (COSTECH). After the due process, a research permit number 2011-51-NA-2010-190 was issued for the period between March 1st 2011 and March 31st 2012(see copy attached in the appendices). In partnership with a local contact person/collaborator other ethical issues were considered. A statement on the principal investigator's commitment to the ethical standards was drafted, signed and submitted to COSTECH (See appendix V).

We undertook to uphold the ethical standards that govern anthropological research. The application to conduct this research also conformed to the requirements for international researchers by the United Republic of Tanzania. In this regard, all the due fees were paid for authorization of the research. To this effect, the principal investigator was granted residence permit, class C (No. 0090717) to further authenticate and legalize the research process(see permit copy in appendices). After endorsement of this study, it was conducted with the knowledge of Regional

Administration and Local Government authorities in Mtwara, and Mwanza. The Administrative secretary for Mtwara and Masasi were notified about the legality of this study (See letters in appendices).

In the fieldwork process, write-ups, and dissemination process, the principal and co-investigator endeavored and will seek to maintain the basic ethical principal in spite of the clearance granted by authorities in the United Republic of Tanzania. In this regard, the ethnographers in this study emphasized that the ethnography is essential to the successful promotion of health and well-being of PWA and other people experiencing bio-cultural exclusion. During the research process, we explained to the participants how we would and will respect their dignity, rights, safety and well-being during the research and dissemination process. Therefore, the nature, purpose and objectives of the study were explained to all the participants before they confirmed their verbal informed consent before other participants. Verbal consent was preferred to written consent by most of the participants owing to their low literacy and personal considerations. While all participants consented to taking of the pictures and recording the conversations on video and voice recorder, they were promised anonymity. Pseudonyms and hidden identity in pictures were promised to conform to ethical standards. All the respondents consented to the ethical researcher's discretion in the use of pictures taken for academic and educational dissemination purposes.

Figure 3.2: The Researchers with TAS official in Dar es Salaam



CHAPTER FOUR

Presentation, Interpretation and Discussion of Findings

4.1 Introduction

In this chapter we present, discuss and interpret study the findings. The data is analyzed using concomitant qualitative techniques and presented in an ethnographic perspective. Verbatim reports from study participants presented to emphasize the patterns of the themes analyzed. In the first part, there is the presentation of cultural responses to albinism in order to show the extent to which current cultural beliefs and superstitions about human albinism constitute a revival of indigenous forms of prejudice and exclusion of PWA. The chapter also examines the effect of current cultural beliefs on the livelihood and quality of life of PWA in Tanzania. This is followed by analysis of how do albino persecutions in Tanzania characterize different levels of poverty and struggle for resources and power in East Africa. In addition, the chapter highlights the socio-economic implications of the stigma against albinism on livelihood security and potential for development. The data in response to the need to understand the lived experience of PWA in the face of superstitions and witchcraft beliefs relating to albinism are analyzed. The chapter will then discuss the in which social and cultural policy in East Africa and particularly, Tanzania can facilitate social inclusion and integration of PWA in mainstream social and economic life. In view of the ethical requirements and the need to protect anonymity of study participants as pointed out in chapter three, pseudonyms are used throughout this chapter.

4.2.0 Conservative Cultural Responses to the Birth of PWA

In traditional African belief systems, occurrence of phenomena that deviate significantly from that which people perceive as natural and ordinary elicit anxiety.

Extraordinary and unaccustomed happenings in the physical and biological spheres of fauna and flora may be unpredictable. Occurrences that people categorized as such are ominous and perceived as portending evil and bad luck. In a focused group discussion (FGD) in Masasi district of Mtwara region, participants reiterated the ancient unresolved mystery of the human albinism condition. Our informants and respondents described such ambiguous states as manifestations of what they referred to as *'tukio la mkosi';* that is, ominous occurrence. In indigenous African worldview, mixed reactions are characterize less archetypal happenings, such as, women delivering children with anomalies; twins, hunch-backs, limb and other physical disabilities. Phenomena that seem to defy accustomed nature of things have continued to elicit, awe, stigma, superstitious myths, and different perspectives on either evil of benevolent power inherent in the atypical phenomena.

The discourse on human albinism in Mwanza and Mtwara entail reports on how communities in Tanzania as in many parts of East Africa draw on spoken or discrete beliefs and superstitions that present people with albinism (PWA)--infants, youths and adults alike-- as ominous epitomes or occurrences (*tukio la mkosi* (sing.) or *mikosi* (pl.)*,* in the family, lineage, or clan. A participant one of the FGDs in Masasi emphasized the fear of albinism-like *mikosi* as an important theme in pre-nuptial counseling by pastoral workers. He said:

> This is common among us pastoral workers dealing with pre-marital counseling. We ask: 'daughter, has there been anyone in your family who has had chronic problems, such as, leprosy, physical handicap (*ulemavu*) or something like that… or *ulemavu wa ngozi* (albinism) because it is good to know…(Religious leader, Masasi district, Mtwara region April, 13 2011).

Sustained discussions about Albinism in this study confirmed the ancient beliefs about perceived phenotypic anomalies, which contradict perceived natural order in the universe. Biological ambiguity manifested in albinism and other unusual congenital conditions attract ambivalent responses that prompt either extreme veneration or stigma of the affected person. Biological uniqueness and perceived abnormality also brings to question the personhood of affected individuals and speculations about their culpability or unspoken guilt within their genealogies. Narratives from the field indicated the existence of a tradition of 'silent mercy infant killing' due to; perceived physical vulnerability & livelihood liabilities of Children with Albinism (CWA). According to popular discourse, birth of CWA "invite war", it is ominous, or concretizes sin or witch machinations in family. In this sense, local cultures in Tanzania seem to have unspoken denial of PWA's personhood. For example, there people say that PWA don't die, or they manifest curses and bad omen variously referred to as *'Peleko', 'zindiko', 'balaa', 'mikosi', or 'laana*'

Many indigenous African societies in the past and at present perceive congenital or even acquired physical disability symbols of misfortune and evil. Paradoxically, indigenous African belief systems associate people with outstanding physical anomalies with power, which can either diminish or increase wellbeing and/or prosperity at both individual and community levels. In order to avoid gross side effects of power from anomalous beings, the people who embody the power would be exterminated or isolated from the rest of the society. Mr. Maji Maji for example, was a successful person with albinism from a rural area in Mtwara. His relative success unlike other PWA was attributed to the fact that his albinism condition was mild. He had the opportunity to work in civil service and even travel to other countries like India, where his condition was not necessarily conspicuous among light-skinned people. He narrated how he was feared, stigmatized and isolated during his time in boarding high and primary schools. He observed that people believed that albinism was contagious. Other pupils and student would watch out for the container he washed his hands in order to avoid it. However, he often took revenge by being the first at the dining hall. I would go and dip my hands in all the containers to see if the rest had any choice of avoiding where I had washed my hands (Mr. Maji Maji).

From another Key informant's report, Yao elders in Southern Tanzania would kill a newly born infant, if they suspected that the infant had the albinism trait.

> They killed it even before it came out saying this will bring adversity to us; it will bring misfortune to our family. So they kill it and announce that 'the child returned before it came out (*amerudia ndani),* yet it would be the birth attendants who would have 'done that work' in order to avoid misfortunes (*kuepuka mikosi)* (FGD participant, Masasi).

Traditional beliefs define misfortunes of this kind in terms of personal causation. Sages would associate such *mikosi* with blemish in personal lives of parents in the current or past generations. For such an occurrence, participants in another FGD reconstructed the popular aphorism for the unfortunate incidence:

> …she (the expectant mother) delivered, but we did not find anything, it returned from inside' (*Aligopwele ngali chapatile aujile nkati [*Yao language] or *Amejifungua, hakupata kitu, amaerudia ndani*-(Kiswahili language). (FGD excerpt, Masasi District, Mtwara Region, April 13, 2011).

However, Key informants indicated that children with albinism would be allowed to live, in isolation, if they were of the third and subsequent conceptions. Birth attendants would decide that 'that is the plan of God after the third incidence of the birth a child with albinism, and spare it to live'.

Most of the PWA who participated in this study tended to concur with the views given by Mr. Tari, an official at UTTS in Dar es Salaam. Following his view, they argued that resurgence of discrimination and segregation confirmed the historical prejudice against people born with albinism. Mr Tari had said:

> These cases are rising now due to… [People's] viewing of albinos as… not important at all… the children albinos in African societies are believed to possess certain powers. There were many of these killings of children with disabilities, which were done secretly...They used to believe that bearing a child with a disability was a misfortune and a bad omen. Hence they were considered to bring bad luck to the

> family and society… they were killed secretly when young… When a mother gave birth to a disabled child be it albinism or any other disability, she used to be convinced that that particular child was useless. They cannot grow up, and even if they grow up they cannot help the family in any way. They cannot dig; they cannot tend the animals nor do anything to help in the family. This made the mothers to agree to their children being killed secretly. That brought about a belief that albinos don't die but they just vanish into the thin air…There three of us with albinism in my family. In total we were nine children but three of us were albinos. Three of my siblings have already passed on so we are now six. Among the three of us who had albinism one died when he was young and he was buried just like a normal human being. His grave is still there. But we have come to learn that albinos used to be killed when young. That is why the issue of killings has been highlighted in since the year 2000. The belief that albinos possess certain powers has also re-emerged in the 21st century.

4.2.1 Indigenous Constructions of Albinism Aetiology

Perspectives on the etiology of albinism in Tanzania as in other parts of East Africa relate to the superfluity of witchcraft beliefs and superstitions in African worldview. Many people who participated in this study associated albinism with misfortune. They traced the perceived misfortune to deeds and lives of deceased kin or envious people preparing medicines, or applying witchcraft to affect the quality of affected other peoples' progeny. Someone might have prepared medicines that caused recurrence of adversity affecting a particular mother and uterine kin or particular matrilineages. This perception featured in explanation of recurrence of the albinism trait in particular families, lineages or clans.

In popular beliefs and superstitions some of the *mikosi* manifested as albinism are forms of heritable suffering. Such misery is considered to be a consequence of transgressions of one or a few individuals in a family's history. This is common in superstitious narratives, for example, chronic diseases such as leprosy, epilepsy and cancer, which several ethnic groups in Southern Tanzania define as manifestations of *peleko*. This is an act where after the death of an evil doer such as a thief or a witch, elders and religious functionaries ritually curse his or her grave (*wanalizindika* *kaburi*). As a result, the evil doer and his or her whole lineage and descendants henceforth become the cursed lot, such that, everyone born in that genealogy cannot avoid a fateful disease such as leprosy or any other consequence of bad omen. Such is the essence and origin of *mkosi*. Drawing on the fear of perceived or unknown misfortune clans or lineages would have their specific bathing herbal medicines, particularly for infants and children to remove bad omen (*mikosi)* or blemish *(balaa)* or neutralize their effects in their families, lineages or clans.

Many people in Eastern Africa, especially the rural folk without formal education, find it is difficult to understand the phenomenon of albinism. As such albinism is among the many biological irregularities that constitute cryptic contradiction to established knowledge of human nature and the natural rhythm of biological forms. This perceived contradiction accounts for various names for people with albinism in Tanzania and the rest of Eastern Africa. *Zeru Zeru*, for instance, is a name for a person with albinism, which has varied stigmatizing and condescending connotations. The linguistic perspectives on albinism similarly constitute initial instance of cultural exclusion from construction of normality, drawing on natural biological exclusion of victims from accustomed categories of normality.

4.2.3 *Unyany paa*: Social exclusion and coping among PWA

At Ocean Road Cancer Institute which houses TAS, there are many postings on the Notice Boards. The notice in figure 4.1 is an important part of the essential ethnographic material. Cursory interpretation of its content below indicates that exclusion is one of the key struggles of TAS.

Figure 4.1 Mission statement of TAS at Ocean Road Cancer Institute

DIRA NA DHIMA

DIRA

Kumkomboa Albino wa Tanzania na Afrika kwa ujumla kutoka katika mtazamo hasi wa jamii, unyanyapaa na unyanyasaji; kushinda vizuizi vinavyomfanya asiwe huru pamoja na kunyimwa haki za msingi kama vile elimu, afya na huduma nyingine za jamii.

DHIMA

Kuwa na jamii shirikishi, isiyo na ubaguzi wala unyanyasaji, na yenye kukuza heshima na utu wa Albino katika jamii.

Source: Picture by first author, July 2011

The title of the notice above (fig.4.1) translated to direction or focus (*dira*) and mission or role (*dhima*) of TAS. Thus, the focus (*dira*) of TAS is:

> To rescue albinos of Tanzania and Africa as a whole from negative perspectives of the society, discrimination and exploitation; to overcome the constraints to his/her autonomy and access to basic rights, such as education, health and other social services.

Secondly, the mission or role (*dhima*) of TAS is:

> To have an inclusive society that neither discriminate nor exploit, and one cultivates respect and the personhood of the albino in society.

People with albinism have to cope with bio-cultural exclusion, worsened by witchcraft beliefs, superstition and stigmatizing labels, which in turn predispose PWA to livelihood vulnerability that is unique to them. It is in this way that myth, stereotypes and language can shape ideas and reality that affect the daily lives of PWA in Tanzania (Mesaki, 2008), and the rest of East Africa. In Kiswahili speaking areas, many PWA are christened, "*Mzungu*" (white person) against their wish'.

Mockery names abound for PWA like people with atypical physical traits; emphasizing their differences negatively and implying livelihood disability labels. In Tanzania the most stigmatizing and marginalizing label for PWA is *Zeru Zeru* (ghost), while in Malawi they are labeled "*napwere*"-that is, 'dry pigeon peas', to denote their brownish complexion when they are dry (Mesaki 2008).

Indigenous worldview in many African societies construct albinism as a disability and the social attitudes towards albinos manifest lack of understanding, fear, and prejudicial cultural exclusion related to phenotypic or physical biological traits of people with albinism. Therefore, African worldview underpins alienation and ostracism of PWA as they are not considered fully human being, as their personhood is ambiguous. This explains popular beliefs surrounding about albinos associating them with supernatural or mystical punishment, or curse. Superstitions abound about giving birth to children with albinism, their immortality, giving birth to albinos and t their spirit-like qualities, such us their ability to vanish and not die. PWA are as such conceived of as anomalies in the society, hence a marginalised and alienated group in the society. Today, the Kiswahili terminology that many people perceive as most appropriate for PWA is or Wa*lemavu wa ngozi, sing. (Mlemavu wa ngozi)*, that is one with disability of the skin. However, the use of concept of *mlemavu* traditionally has strong indications of handicap, or disability or incapability, which for many people, with regard to PWA may include the perception that being an albino implies lower intelligence.

While people with albinism may have mental and physical abilities like the rest of the citizens, social and cultural labeling shapes their resignation to the status of disability. This was confirmed by most of the respondents with albinism. A mother to a 16 year old school girl with albinism in Magomeni; Mtwara interjected her:

> Just answer that it is a disability. It's a disability… I think it is a disability. Why aren't other children like her? It's a disability. Disability of the eyes, hair, skin and all the body parts... (Mama X).

In Makindani; Mtwara, respondents had different view about the label of albinism as a disability. One participant in a FGD said:

> …I think it is an act of God... We cannot understand why it is like this…Jonie (a 16 year old PWA) is disabled due to the colour of his skin…It is a disability. God planned it to be like this.

Jonie's mother interjected:

> His condition normally makes me sad. He cannot go out often and I'm afraid of enemies and other bad people. He cannot socialize well with other people. He also has to forego some leisure activities. He normally has to stay in the house, in homestead. We cannot send him far… He only goes to the market and comes back immediately. In the household there is no discrimination, we are only afraid when he goes out on his own.

A few respondents, especially family members; caregivers and guardians did not prescribe to the view that albinism was disability per se. They indicated that it would not be the basis of discrimination even beyond the family, for example, in schools. With regard to the latter, Jonie observed: '…They treat me normally just like other children in school…' Some family members seemed to be tactiful, talking about albinism, disability and discrimination in group discussions where PWA were present;

> People say they (PWA) are disabled because their skins are different from ours. And if their skins are different yet some of us are light skinned and others like us are dark skinned, how does her skin colour become a disability? I'm surprised about that and I have not found an answer. Is there anything that they cannot do because of their skin? Sometimes they talk about the albinos, the way we should take care of them. It requires us to take care of them and protect them. Personally I have gone to the (TAS) representative and the chairman because of my younger sister Ziliara. I have to take care of her... Personally I don't think I can take care of her since she is a human being just like the rest of us. Is there anything else that they cannot do like other people due to albinism? Let's say like studying like the others... Normally they do everything like anyone of us (Malisa, Mtwara-Magomeni April 2011).

The sentiments expressed in the excerpts above belie the extent of social exclusion or discrimination (*Unyanyapaa*) of PWA in Tanzania as in other parts of Eastern Africa.

Many people would fear the birth of an albino as an epitome of reproductive catastrophe resulting in progeny of unknown origins dubbed as *zeru zeru*. For the Yao in Southern Tanzania, the term *Zeru Zeru* has evolved to mean a person whose origin is unknown or one referred to with a meaningless or worthless, shocking even family members. Such interpretation is couched in a common expression among the Yao on the birth of a child with albinism. Birth attendants and people around would be heard exclaiming as they report the birth of a child with the stigmatized biological trait.

The spate of disappearance and brutal killing of People with Albinism (PWA) in Eastern Africa, with a higher concentration of related reports in Tanzania motivated the present study. Oral tradition affirms that a negligible population of PWA would have survived beyond infancy in past indigenous African cultures. Those who lived on were probably venerated, yet they were never known to have died normally and buried. Popular reconstructions of myths about PWA report that youth and adult PWA just disappeared. Such myths and related beliefs, and superstition seem to have been dramatized in the epidemic-like mysterious deaths and brutal killings of PWA in Tanzania and elsewhere in Eastern Africa. The ethnographic puzzle in the nearly three decades of deaths of PWA related to witchcraft, superstition and a wider spectrum of obscurantism relate to how such ominous embodiments have evolved to be associated with tokens of prosperity, well being and magical portions against the same evil they embody in indigenous African systems of belief and thought.

4.1.1 Livelihood Context of Albinism Beliefs

Explaining how the albinism condition affected their daily life activities, Mama X said:

> The life we live is not a life... The way we live with my child is not life at all. All our life we have to be supported, even for the school fees, I have to be assisted. Some assist us half-heartedly. Yet I'm required to make all the contributions yet I'm already overburdened, without means…her father is already dead. Sometimes back I used to do farming so that we could something to eat. But now life is very hard. We have no life at all. There are numerous contributions that I have to make. The building [fund at her school] requires fifty thousand shillings, yet I totally have no means. The watchman's pay is still pending. They brought me a paper yesterday

> requiring me to pay five thousand shillings. Yesterday she came crying saying she is required to pay ten thousand shillings school fees. But where can I get the money?

Like other countries in the Eastern Africa region, people in Tanzania engage in numerous activities for a living. The most common livelihood activities range from hawking of assorted items, subsistence farming, to small scale businesses in major towns and markets. People without albinism strive hard to make ends meet, sometimes leading to seeking wealth through mystical strategies that may involve superstitions on how magical practices involving items, object and body parts associated with PWA. In an attempt to make quick money, some people (especially middle class and the rich investors), believe that there are magical and mystical powers that could extremely increase their resources especially finances and other opportunities almost instantly. According to some respondents as revealed by Rukia, a person with albinism and a trader in a food kiosk in Kitogosima, Mwanza:

> Uwezo wa madawa na miujiza upo. Ni kwa nini Mtu awe na biashara abayo haivutii watu wengi, hili hali mwinginge hapo hapo kado, ana wateja wengi na wanauza vitu vinavyo fanana zenye bei inayolingana?" (The power of medicines and miracles are reality here. Why should a business person have that attract fewer customers while the one next door in similar business, selling at the same prices attracts more customers?).

Mzee Mrema on the other hand asserted that:

> Mapato waliyonayo matajiri yanatokana na utumishi wa majini ili kuwaletea wateja na kuwazalishia mali, hasa hasa Waarabu, ambao huwa na itikadi ya utumishi wa madawa*"*. (The income that the rich have originate from the service of jinns (spirits in Islamic mythology that appear in human and animal forms to possess human beings), which bring them customers to help them generate wealth, especially the Arabs who have superstitions about the use of potent medicines).

Due to such beliefs, there were narratives about business people known to seek magical powers. The popular beliefs that body parts from PWA, treated by traditional medicine men with magical portions would attract wealth abound in narratives in the present ethnography. Most participants in FGDs in Mwanza claimed that anything associated with a person with albinism, be it their hair, skin, hands, tongue, eyes, legs and more specifically the private parts was associated with good luck that could lead to prosperity. It is for this reason; the poor people are lured to hunt for PWA to fetch any of their body parts. Mrisho from Kigagama, Mwnaza, however, affirmed that body and animal organs are commonly used by witches and witchdoctors, although the episodes involving PWA heard for the first time in early 2007, with most cases emerging in 2009/ 2010.

Kayozi, a Key informant from Mwanza argued that households with PWA shockingly found soil in places where they bath, scooped away almost on daily basis by unknown people. This people eventually tie a portion of the soil to their garments as a source of good luck and security against witchcraft. PWA however, due to their susceptible skin, weak vision and fear of being attacked, are unable to persistently work under the hot sun rays to earn a living like their counterparts. These issues make them vulnerable to more risks than other people under the same circumstances. One student with albinism, studying at St. Augustine University in Mwanza asserted:

> Ours is a complex situation right now in Tanzania; if albinos work for long hours, they risk being caught and killed or some body parts chopped off and they are left for the dead as it has happened before.

An official from Tanzania Albino Society (TAS), Mwanza similarly regretted that PWA could not work consistently in the sun exposes risks contracting skin infections that could easily degenerate to skin cancer. Conversely, if they would opt to stay home, they risked lack of basic necessities including food, clothing, health care, education and hence end up being quite poor in society or they could even die.

4.1.2 Lifelong Stigma, Exclusion and Livelihoods Issues

Contrary to what people know, subtle stigma leading to discrimination of PWA begins in their families. Dalipoo, a 40 year old person with albinism in Masasi, Mtwara observed:

> I faced such challenges many times… in my pursuit of education. I studied up to class seven [in primary school]…I sat for the exams three times without being fortunate to get an admission to high school. I really don't know the reasons that led to my not being admitted to high school. I don't know whether I failed or what was really happening. I was never admitted to high school. I realized that in those days it was a bit hard for albinos to access education… My [other] best example was at home... You know when we are born, even for our parents to take us to school, it was a big problem…They used to take the normal children to school and leave us at home…You see, when we are in class we have to sit on the front rows. But still when the teacher writes on the board it is still a problem to read what is on the board. So we normally had to stand, walk to the board, read what is there and then come back to your desk and write. This would happen many times leading to the other students calling us names and also insulting us… In some parts and areas that we have been to, people told us that there was a lot of discrimination even in hotels. They said that people could not eat together with albinos and if an albino washes hands in the tap the others don't wash their hands on the same tap.

The sensitivity about discrimination, murder and insecurity among PWA and an attempt to protect the authority's reputation locally and internationally, partially affect the level of openness about the plight of PWA. This partially contributes to the dexterity regarding information on such matters. However, alternative sources such as the civic society, religious leaders, village elders and community members filled the gap in providing their own reflections on the subject matter.

Mr Magoma, a person with albinism from Shishani village in Mwanza lamented: *"Maisha yetu ni ya dhiki mno. Majina tunayo itwa ni ya fedheha na kuto heshimiwa".* [Our lives are full of frustrations and sadness. The labels we are accorded are a great shame and disrespect]. "Wewe fikiria majina kama Mbirimiru" kumaanisha, kitu au mnyama mwenye madoa doa ama vipachiko pachiko kwenye gozi, mfano wa fisi), Think about names like *Mbirimiru* meaning, an animal with spotted skin like a hyena. Names were given to PWA with varied interpretation, for example, some interpretations of *Zeruzeru* denoted mean 'ghost' 'Jinn or devil. Some people referred to the PWA as, diri (income 'deal'), *Mzungu*, or *Mzungu likonde* (derogatory reference to (fake) 'white person'), *Cheupe* (A whitish thing). *Mwarabu* (an Arab), *Mchina* (a Chinese). Tanzania Albino Society (TAS) endeavored to fight the socio-economic injustices and prejudices that are associated with these labels. The labels dehumanize PWA, stigmatize them and reduce their dignity and plight to that of a less human person in their own country. These issues make them lose their worth, dignity, self esteem and confidence in society.

4.1.3 Social Labelling and Livelihood Security among PWA

Stigmatizing labels reduce the confidence of PWA, since they feel less important in society. Everywhere they go, they are being looked at as a peculiar species of humanity. They assume that people are always thinking and talking about them. "Sisi hujihisi kama hatuna uwezo wakutenda na kuishi kama watu wengine wa kawaida", asserted Mzee Malecha in Mwnza. [We perceive ourselves as less competent hence unable to compete at the same level with others]. Other people think that PWA are not as attractive, academically or otherwise bright, innovative and organized like the other members of society. Due these labels, most people disassociate themselves with PWA which denies them the right to association, a sense of belonging and affection. As a member of a FGD in Mwanza asserted:

> Unyanyapaa na kutengwa, huwafanya wasichana walio na ulemavu wa ngozi wasiolewe. Vijana huwa wanataka kujua kama waschana walio na ulemavu huu wako kama wasichana wengine kimapenzi. Hii ndio huwafanya wengi wao kupata mimba nje ya ndoa. [Stigma and discrimination make girls with albinism not to get married…Most women with albinism are not married, although men usually use them to out of curiosity to explore whether they are like the other women sexually. This is what makes most of them get children out of wedlock.

This trend affects their means of survival leading to single parenthood, abject poverty, discrimination and neglect, especially the women and their children", Zainabu claimed: "Wanaume wengi sasa hivi, huwa wanatamani wasichana wenye huu ulemavu wa ngozi, wakifikiria wanapata wazungu kimapenzi, Hii ni hatari sana kwa kuwaabukiza wengi wao UKIMWI, na magojwa mengine ya zinaa*"* [Most men pursue these ladies with albinism sexually, assuming, that they are like white women, which exposes women with albinism to HIV and AIDS, and other sexually transmitted infections].

4.1.4 Emotional and Social Effects of Discrimination

Discrimination and fear often makes PWA be emotionally detached from other people. In most cases, they live quiet and isolated lives at home, with little exposure and interaction with other people in the neighborhood. In Misungwi district and the outskirts of Mwanza Town, Milkah, an official of the Albino Society in the region, observed that; “nowadays you never know who your genuine friend or neighbor is. Sometimes, a close friend might be planning your execution”. She was referring to the incident which involved a Kenyan man, who was convicted to 17 years in prison, for planning to sale his Kenyan friend with albinism in Mwanza in August, 2010 for Tshs. 400,000,000 (Kshs. 22,405,235) (US$ 263,591). Milkah lamented; “We know we are still alive and secure, when we see the morning of a new day. Urban or rural environments are quite insecure for us in any country in East Africa”.

Most PWA are suspicious of strangers owing to ubiquitous cases of unspoken or manifest prejudice against them. Many respondents in Mtwara and Mwanza said that PWA did do not trust and/ or take up jobs in towns and isolated places. This trend restricted their survival to activities around the household, homesteads and village trading centers, yet most opportunities are available in urban places away from their parental home. A children’s officer in Magu, Mwanza observed that:

> Most households cannot employ PWA as house helps or gardeners. They claim that children fear PWA. Others claim that they will transmit cancer to their children. Men with albinism are said to be lazy, since they can hardly work under the hot sun rays.

This fear and anxiety has made most children and the youth with albinism who were targeted by ‘albino hunters’ to be taken to special schools like shule ya Msingi, Mitindo, in Misungwi. Such schools are presumed to be more secure than having children with albinis walk daily to school within the villages, especially in Magu, Geita, Misungwi, Segerema, ukerewe and Bariadi, according to Tanzania Albino Society (TAS). This initiative is partly supported by the Under The Same Sun (UTSS) an NGO, founded by a Canadian with albinism, which provides educational support, materials, equipment, medical assistance and awareness and fights for the basic rights and protection of albinos in Tanzania.

While some respondents in Mtwara and Dar es Salaam supported initiative for exclusive social development for children, youth and adults with albinism, others thought that such programmes amounted to official isolation of PWA. Two participants in a group discussion in Mtwara; Mikindani also supported this view. One of them; a PWA said that he would support such programme as it would be catered for by the government, to have PWA live separately.

> …they will go to schools for albinos only. That is there will be special schools for albinos and other schools for the normal people…It is okay, they are just human beings like others and they will be taught just the normal children. I don't think there is any problem. If it could happen here I would really be happy.

However, several other respondents said that this would institutionalize low esteem among PWA, who have to come back to the mainstream society after education and vocational training. One informant in Mtwara said:

> Although there is no problem, we live here with other normal people yet there is no problem with them. We are all human beings and so far she (the family member with albinism) is not being exploited in any way….We encourage them to feel just like other normal human beings.

Prejudice against PWA characterizes the general condescending attitude with regard to their abilities. This relates to the notion that PWA are worthless, less human, and not as gifted as people without albinism. This frame of mind and local worldview contributes to exclusion of people with albinism from participating in social, economic and political processes that would be beneficial to them and society. Many people who participated in this study blamed this scenario on 'inadequate education in society and low concern about the need to educate the society'. That is lack of awareness about the potential to excel in all sectors of economy and social development.

A participant in a FGD in Masasi; Mtwara, for example asserted:

> Many people are surprised to hear that there is provincial administrator who is an albino. They really question the possibility and truth about this. Many are also surprised that a Member of Parliament (*mbunge*) can be an albino. They normally ask: 'Even a member of parliament can be an albino? How comes? Do you get it? They do not say that their Member of Parliament is an albino, but they ask a Member of Parliament can also be albino?

During the ethnography on which this monograph is based, there were narratives disapproving the age-old notions that demeaned the personhood and abilities of PWA. In Lindi region to the north and east of Mtwara, for example, an elected member of parliament was a person with albinism, contrary to what many people would have expected. In addition, several study participants with albinism in Mtwara person is had served or were serving in the provincial administration. From thses cases and others in Mwanza and Dar es salaam, it was dawning on common citizenry in Tanzania that PWA has the potential for social, economic and political achievement if they had the chance for appropriate education and mentorship.

Participants in an FGD in Masasi were unanimous about the view that the mechanisms put in place in Tanzania to promote the welfare and rights of the people with albinism were not sufficient. At this point advocacy is very important. We may be saying one thing, but doing the exact opposite. We need to have advocacy to ensure that what we say is what we do. In addition they stressed the importance of evaluation of existing programs and strategies intended to enlist the participation PWA and other people with perceived disabilities programmes to ameliorate lives of poor citizens. A person with albinism who participated in one of the FGDs in Masasi; Southern Tanzania decried the squalid and low quality of life and livelihood conditions of PWA. He observed:

> Our lives are pathetic… We live in the villages and as you know life in the villages is very difficult. We cannot do strenuous jobs in the sun and such things…. we do not meet most of the basic and important needs that we require. Nowadays there are NGOs that deal with the issues of albinos; do you know any of them? We don't know them. Have they been established here? None has been established so far…

4.2.0 Notions on Albinism and Witchcraft Beliefs Puzzle.

Many knowledgeable and uneducated informants in Mtwara reiterated the themes of ignorance, illusion and stifled innovation in relation to witchcraft beliefs in East Africa. Several key informants in Mtwara rural, and peri-urban areas, Mikindani, and Dar es Salaam further related these themes to witchcraft belief and superstition associated with albinism in Tanzania. Nearly all PWA who participated in the present ethnography supported this sentiment.

According to a key informant in St. Augustine University in Mtwara, it would take millennia to move from ignorance and illusion to appropriate livelihood and daily life innovations. In this regard, Mwalimu Matoi the key informant noted:

> Africa and areas where albinism signifies danger to victims of the condition in Tanzania, particularly in Shinyanga and Mwanza, are still in the ignorant and illusion stages since they believe that if you want to get rich you just need to kill somebody [person with albinism] and out of it you get rich… (Mwalimu Matoi, Mtwara April 2011).

The above view is pervasive among contemporary Tanzanians. However, most of the respondents in the present study had ambivalent responses to the perceived veracity of superstitions and witchcraft beliefs related to albinism. Indeed, hazy beliefs linking PWA with mystical power and origins are ubiquitous in popular discourse in Tanzania today as aforementioned.

The data from the field indicate that the government and other social actors are yet to determine the extent to which PWA are killed, or mutilated for magico-religious rituals. Informants in the Southern Tanzania ethnographic sites alluded to the need for 'courage for society as a whole to move from these lower stages of ignorance and illusion to pave way for modernism 'Mwalimu Matoi in Mtwara town asserted:

> We should invest in innovation, in critical and clear and creative thinking… Otherwise we keep on moving with this "Ungo Technology." They don't want to study physics and chemistry to make an aeroplane. They want to say that they can fly from Sumbawanga to Zanzibar overnight on "Ungo." This is nonsensical and illogical… It is important to be innovative and to be critical. We should ask ourselves, everybody individually, collectively, every political party and as a nation nationally. Let's us ask ourselves if we invest in these illusions could we make a step further ahead or backwards.

Ungo in the above excerpt refers to a winnowing or sifting basket, which could symbolically be used in divination. Credulity in the outcome of divination through '*Ungo technology'* sustains witchcraft and magico-religious beliefs. Most informants blamed persistence of such beliefs on 'inability of the people to ask critical questions' at individual, collective and national levels

Several informants concurred with the view that the nation has the responsibility to unravel the mystery of albinism and witchcraft. This was partly because some respondents insinuated that political actors hand a role in the pervasive witchcraft, sorcery and magico-religious activities which affected PWA by extension. One informant in Mikindani; Mtwara said:

> Our politicians should avoid looking for cheap solutions that blur people's beliefs and at the end of the day they are not solutions... They are temporary solutions or not solutions at all. They just damage lives of people. So they keep on saying, okay go and kill some people and get their body parts and their private body parts so that we become rich... And some people coincidentally believe that. But the coincidence is minimal. But it looks like it is the politicians who send the people to kill the albinos.

The discourse on how ignorance drives witchcraft beliefs, which have consequences on the security of PWA in the Lake region (Mwanza) characterized responses in

Southern Tanzania, too. Mtwara for instance was relatively calm with regard to persecution of PWA as pointed out earlier. Some informants in Mtwara and Dar es Salaam referred to other area such as Shinyanga, Sumbawanga, and more specifically Mwanza, as so wild in relation superstitious human killings not limited to PWA. Mwalimu Matoi, in Mtwara for example, observed:

> One thing is that the Lake Region is known for witchcraft beliefs associated with human sacrifice. This was even before the culture of killing albinos. Human sacrifice has been commonplace. Now this new development of killing albinos is beyond belief. It is 'new medicine'. It is 'modern medicine', 'modern sacrifice' for those in fishing especially along Lake Victoria and mining. We have the largest mining companies in Geita, mining diamond and gold mining. These are very huge mining centers in almost the whole of sub-Saharan Africa. They are really involved in human sacrifice. [They believe that] when someone dies there, then you find more. Yes. Even in Arusha with Tanzanites mining activity... Offer human sacrifice, you get fish… human sacrifice, you get more gold. It is a belief… a stupid belief…

Respondents in areas with lower reports of direct effect witchcraft activities on PWA indicated awareness of indirect consequences.

As pointed out in chapter two and three, the issues in the livelihood of PWA in Tanzania are part of a regional cultural continuum. Respondents indicated awareness of unique aspects of witchcraft beliefs that aggravate the fear and anxiety in the PWA community. Narratives in the present study intimated that an understanding of the witchcraft beliefs that would affect people with congenital anomalies as PWA spread beyond Tanzania to the rest of the Eastern Africa coast.

> From Mozambique to Kenya; you start with Mtwara, Lindi, Kilwa, Dar es Salaam, Tanga, Mombasa, Malindi and areas around the coast... This is very common. This culture is impoverishing... If you look at the coastal areas of Kenya and Tanzania the people are very poor. And everywhere where people believe in witchcraft the people are very poor. And I ask myself, should they keep on investing in these types of ineffective desperate syndromes…If these people [witchdoctors] are saying that they can make money and they can do wonders they should do that. You go to a witchdoctor and he tells you that he can give you a good house and make you a millionaire and give you a car but he is sleeping in this miserable *makuti* house. Or he tells you that your child will go to the university, yet his child never went to class one…psychologically it affects people, if you keep on insisting that you will be

> harmed then it will happen. And you know most of the diseases are emotional. Mr. Mukaido, Mtwara).

4.2.1 Albinism and Lived Experiences of witchcraft

PWA who participated in the study in Mtwara narrated challenges related to witchcraft belief and superstitions owing to their condition. A care taker of a youth with albinism, for example said:

> Zolaga is normally attacked mysteriously at night. They normally injure him at night. When he wakes up in the morning he is injured. When I enquire they say that it is all witchcraft because of his skin colour which the witches and wizards love…The attack normally occurs at night when he is asleep. When he wakes up in the morning he is injured. When I enquire they say that due to his skin colour the witches and wizards love his blood. They come mysteriously; it has to do with their witchcraft. It occurs from time to time. The counselors say that when this occurs I have to seek protective charms from a traditional healer. The traditional healer gives him some protective charms so that the witches and wizards can stop following him. …They normally follow them and kill them. But they are still at risk even when they don't venture out during the day.

A similar view was held by a person with albinism who participated in a group discussion in Masasi; Mtwara. He said that it happened to him once as he woke up to find some unexplained incisions different places on his body. He said: '

> I went to a traditional healer and he told me that it had to do with family issues…He gave me some herbs to use and he also tied some charms on me. I continued living safely until I gave the amulet to my sister (Mr. Inyangala)

In the same group discussion, a female with albinism observed:

> Personally I thank God that such a thing has not happened to me. I have gone to many places and done so many things. I have also met with different elders. When I walk around at night I'm not afraid of anything. This is because of the way I carry myself... It also has to do with your faith. Yes... But there are people who still complain that at night some things do still do happen to them. This shows that these things do happen. Yes, they happen to some people but personally I have not experienced this at all.

These beliefs intensify fear and xenophobia in the daily lives of PWA. Mr. Maji Maji and other PWA interview in Mtwara said that they always lived in fear as children and youth. They feared unforeseen attacks for their body parts. They often felt insecure in the kind of houses they lived in—semi permanent houses with wide eaves. It was believed that vampire witches would look out for PWA to take their blood. In fact, Mwanahuruma reported the on occasion she woke up to find bruises when she believed were inflicted by witches' spiritual beings that were looking for her veins to suck her blood. The positive influence of the power would be harnesses through either veneration of the stigmatized individuals or magical harnessing of their body parts or items they are known to have been in contact with overtime.

Many versions of lived experience of witchcraft beliefs and superstitions emerged from FGDs and indepeth interview in the ethnographic sites in Mtwara region. Witches and wizards were said to get to attack PWA either physically, or through the use of mysterious and supernatural powers. An informant in Masasi said:

> …for instance when you sleep, they attack you in your sleep or they cut your nails and hair... That normally happens. You may try to comb your hair only to find that you have no hair, yet you did not have a haircut. So you just wonder where the hair went to… This has however not happened to me. It only happened to my sister in her sleep… My mother was surprised how the hair was cut. There was nobody who had entered the room…Concerning witchcraft and wizardly practices and the albinos, we have heard from the media, both TV and radio about these issues. This really scared us. We here in the south have not been so much affected but it was reported that the albinos in the north were being attacked.

The data indicated that while there was a lot of information about persecution of PWA in Tanzania, not very many of such cases were known in Southern Tanzania. As pointed out in chapter two and three, Southern Tanzania is part of the Southern Africa area of the ethnography of albinism. It was pointed out that in this culture area, PWA would be abandoned by their kin, but were not victims of extremely heinous atrocities as in the North and lake zone of Tanzania. However, several informants indicated that ubiquitous reports about the plight of PWA elsewhere in Tanzania made them experience both physical and livelihood insecurity. One informant said:

> ..But after getting the reports from the north we felt we needed to prepare ourselves to protect the albinos in the south. We started by organizing forums that brought the albinos together. We brought them together and took a census of ourselves. We agreed that we would look out for our brothers and sisters. In case one of us disappeared we would ask and inquire about his disappearance.

Uchawi (witchcraft), Uganga (traditional medicine) and Waganga (Traditional medicine men/ women or witchdoctors) are a common reality in Tanzania. Quite often, most respondents narrated cases of relatives being admitted in traditional healer's wards for long-term treatment processes. Beliefs in magic, witchcraft, sorcery and superstition are commonly held. Mustaffah confirmed that witchcraft is real. (Uchawi upo hapa nchini). "Usipojihadhari na kujikiga na familia yako, basi hamtaendelea" [Unless one is well protected with his family members, you would never prosper in anything in life.]

The above narrative reveals the extent to which Tanzanians regardless of their status belief in superstition. For instance, during this study, when Mbilikire Mwasavile (a religious pastor) in Loliondo near Arusha discovered a herb that could treat numerous illnesses as he claimed, many ordinary and senior Tanzanians, and people from other nationalities flocked his homestead for the wonder traditional drug. Many people (specifically in Tanzania) still believe that their social progress could be influenced through magical means. This explains why many traders believe that body parts from PWA would make their businesses prosper against those of their competitors. People in mining areas of Geita, in Mwanza, for example also participate in fishing industry in Lake Victoria, trading especially in transport and hospitality, politics and administration are among the users of albino body parts in collaboration with some witchdoctors.

The above claim is disputed was mama Kajama (a healer), who argued that, only inexperienced witchdoctors or healers, could engage in dealing with albino parts to gain fame if there are some of us doing this sort of injustice in Tanzania.

[Ni waganga badia, wasio wajadi; wasio na ujuzi na ukakamavu, ambao wanaweza kujiuzisha na unyama huu. Sisi waganga wa jadi, hatuusiki kamwe na mambo haya"].

To the contrary, Rukia a primary school teacher argued that without being mixed with some charm or magical potions, the albino body parts would have no effect. [Bila madawa na kufanyiwa kafara na waganga, sehemu za albino zinazo katwa, haziwezi kufanya kazi]. Surprisingly, fishermen we interviewed at the coastal strips of Mwanza and Mtwara did not confirm that indeed they had used or heard about people who had been using albino body parts to influence success in fishing expeditions.

Mzee Moliwaa Mutihimana of Mwanza narrated a case of shocking experience. “Watoto wasipo tibiwa na kupewa kiga kamili, hawawezi kusoma kwa usitadi katika eneo hili. Ni nadra hata wengine wawache masomo kabisa na kuwa wendahoi mitaani” [If children are not protected against witchcraft, they would never succeed in learning. In fact, even others may drop out of school indefinitely and turn out to be hopeless in the streets]. It is common for people to pursue contemporary treatment and still visit a traditional healer to be sure they are fully protected, even strict religious believers/ followers actually use this double cover. This is common in most parts of Tanzania. However, not all the people engage in this practice. Msafiri, a medical nurse affirms.

4.2.2 Superstitions and mystical Beliefs in Tanzania

> “Ingawa maisha na utamaduni wa Watanzania si tofauti sana na ule wa watu wengini, dhana na itikadi za uchawi na ushirikina ni nyingi mn*o*” [Although the life and culture of Tanzanians are not different from those of other people, the notions and customs of witchcraft and obscurantism are too much, in Tanzania. (Senior Education officer, Msungwi, Mwanza).

The informant above further lamented that, over the previous six years, more than 3,000 people had been lynched in Tanzania by frightened neighbors who thought they were witches. The Legal and Human Rights Centre (LHRC) in Tanzania recognized the seriousness of witchcraft with regard to negative implications for local communities. Further still, between 2005 and 2011, Tanzanians lynched an average of

500 people per year on suspicion of witchcraft, with most killings occurring in rural areas in the north of the country (Mwanza and Shinyanga).

In Shinyanga province for example 242 people were killed because of local beliefs in witchcraft between January 2010 and January 2011 alone, (Legal and Human Rights Centre, 2011). If this is the case, then there are two forces in play. The older generation is associated with the vice, but the younger populations are against the practice.

Most of the reports about witchcraft indicated that victims of witchcraft accusations were older women. They were alleged to have developed red eyes, which some local people consider a sign of witchcraft. However, the cause of this condition according to some key informants is the frequent use of dry cow dung for cooking rather than firewood in some areas. The use of low quality biomass fuels like cow dung cause indoor pollution which is a hazard that affects the eyes. Informants confirmed that women who were considered witches were often killed within a short period of time following the death of a relative. Families visit soothsayers to determine the cause of death and people in the neighborhood would often implicated, leading to the mob killings to deter further bewitching of innocent people. These are the people who were believed to use all means, including albino body parts to increase the potency of their witchcraft substances. Kimaro and Gereja argued in one of the FGDs in Mwanza:

> Rural villagers driven by superstition have also murdered a great number of albinos in recent years due to a belief that making potions from their body parts such as legs, hair, hands and any other part can lead to great wealth. Business people also buy and burry such parts under their business entrances, after they have been cleansed by witchdoctors. This is believed to attract customers and wealth.

Rehema, a woman with albinism in the outskirts of Mwanza town observed:

> We are attacked and raped by people who think that we are different from the other women/ girls. Most of us have children out of wedlock because Men think we cannot

> make good wives, we are expensive to maintain and we can’t work due to our delicate skins. This explains why most of us are single mothers. We are still seen as special beings from heaven.

A focus group discussion participant at Bujora Catholic cultural centre, Mwanza, confirmed one of their fellow discussants’ views that ‘PWA are believed to come from the devil, they are not human, they do not die, they simply disappear’. In addition to generalized poverty among Tanzanian peasant, witchcraft beliefs and superstitions about albinism make PWA and their families doubly disadvantages. They live in typical abject poverty (see figure 5.1 in chapter 5), misery and illiteracy in a society where personal efforts for achievement have the potential to salvage people out of ascribed status. Ironically PWA are regarded as a source of wealth by those who hunt them. This is paradoxical since; if that was the case PWA would have transformed their own livelihoods drawing on the power people ascribe to their condition.

Unfortunately in Tanzania, even the educated elites often seek for alternative medicine from witch doctors for various reasons.

> You cannot separate witchcraft beliefs from the issue of poverty and social impoverishment. The more developed people are, the less they believe in such things like witchcraft, due to influence of modernity and enlightenment" (An official in the ministry of education Mwanza).

Muchuma from Kisesa in Magu observed that there are many true and false stories about albinism:

> I was born and grew up in Bariadi where we were told extraordinary things about albinos. People believed these people never died. Their graves were never seen. They were believed to just disappear and vanish to the sky! However, when we relocated here in Magu, I have seen many get ill and die mainly of skin-related cancer complications or other ailments. Some months ago people lynched a West African Man in Bundi. There was a rumor that people from those nationalities had “jujus” (witchcraft) that made penises disappear if they had any crunch with you, so that you would pay them to get the organs back”. Therefore, witchcraft affecting PWA is a reality.

Muchuma produced a new-paper cutting with this story.

4.2.3 Perspectives of Healers on the Plight of PWA

In Tanzania, the bulk of atrocities against PWA are associated with traditional healers and witchdoctors. There is a narrative that construct traditional healers (*waganga wa kienyeji*) as the appropriators of items linked with albinism for therapeutic, preventive and even potent harmful magic. The irony of this is that, as pointed out by some PWA in Mtwara, they also have to visit healers for protective and therapeutic *materia medica* when they feel threatened by obscurantism against them. The healers interviewed in Mwanza and Mtwara denied the alleged link between their activities and the tribulations among PWA reported in the media and popular discourse. A healer in Mtwara indicated that the mystery of the deaths of PWA would be unveiled if this trend was investigated as criminal activity rather than aspects of healing and witchdoctor business per se.

Arguably, murders and amputations of PWA in Tanzania are associated more with obscurantism than traditional healing. These may also be indicators of general lack of security and cases that belie of criminal activity; contrary to what may people believe. In depth interviews confirmed that the problem of PWA is not only with insecurity posed by those who hunt them physically. They have myriad livelihood concerns that they require to be addressed. Some informants indicated that the 'hunters for body parts' are not healers, or witchdoctors themselves, but 'businessmen' engrossed in the political economy of marketing albinism as a source of power for material prosperity. They are essentially middlemen seeking to improve their livelihood. On the other hand, healers and witchdoctors seek ways of mediating the in the *life worlds* of people with troubled livelihoods, yet healers, 'witchdoctors', the business people and PWA alike crave to increase their livelihood security. Najma, a female youth with albinism, and resident in Mtwara for instance said:

> Some witches and evil people seek the power from PWA, spiritually…they invisibly make incisions on my body at night (wananichana usiku). I need to see an 'artisan' (fundi, figurative for sorcerer) to protect me from undue spiritual access to my body at night by those seeking my blood.

The mysteries of witchcraft and sorcery activities that harm PWA as shown above are also in the public domain in Tanzania and the rest of Eastern Africa. Mr. Mayenga, informant in Misungwi, Mwanza recounted a horrendous story in which a woman called Lebeka had been told by her family elders to dress her baby with albinism entirely in black and lay the little girl in a hut, alone. The mother didn't understand the reason for the instructions, but all the same she obeyed the elders. According to Mayenga, this reveals some collaboration between some elders and albino hunters. The elders, according to this informant knew what would happen to the baby:

> Some hours later, unknown men arrived and went straight to the hut (implication that they had prior information about where the baby was at the time). They used a machete to chop off the innocent child's legs. Then, they slit her throat and poured the blood into a pot and drank it (Mr.Mayenga).

Mayenga showed a cutting from the news paper about the story. Then he concluded, if these people were never arrested and prosecuted in any court of law in this country, how then do we wipe out this problem of albino killings? He wondered why, most buyers of these albino body parts have never been arrested. He alleged that it could have been due to their authority and power in the political system and he added:

> In fact, some preachers in the present day liberal churches are said to use the portions to pull huge followers (brethren) and make money. This is a crazy trade, it happens even in religious shrines!"(Mr. Mayenga, Misungwi)

If these allegations hold water, in our view, then the albino business could be more widespread in societal practice than most people assume.

4.2.4 Religious leader's perceptions

According to religious leaders who participated in the study in Mwanza region, there is a lot of exaggeration in the media and other reports being relayed to the public. In particular, the Catholic Church strongly condemns the killings and bold attachment of some people to traditional practices. But, they are quick to indicate that communities' cultural values are an important foundation of their identity, although retrogressive practices are immoral and should be discarded according to the priest in-charge of Bujora parish and cultural centre.

In Mwanza, a leader of the Assemblies of God centre held a similar view, adding that the church should embark on a spirited war against outdated practices like witchcraft which is deeply rooted in the peoples' culture in order to fight albino and other human killings in the long-term. These leaders reiterate that the criminals should be heavily punished especially those who order and buy the body parts to deter the trade. The religious movements should strengthen the moral and ethical value systems of the society in their spiritual teaching.

In Mtwara, religious leaders presented a typical common concern about exclusion of PWA from mainstream society in Tanzania by their inadequate access to education. A church leader in Masasi; Mtwara for instance reiterated:

> 'We may have many different programs and strategies that are not in line with the expectations of the albinos'. If we could get an opportunity to help them advance their education up to a certain level, this could really help them. This can be done through evening classes among other programs... For instance, the secretary of TAS here studied up to class seven but when they need to get any aid or donation they have to write a proposal, surely how can a person who studied up to class seven write a proposal? Others went up to class four, others never went to school at all how can these people write a proposal to get donations and other assistance? Even when you bring them that donation how will they know how to use the donation? For sure the primary need for them is to get an education...

4.2.5 Experiences in High Risk and Low risk areas

While low risk areas along the coastal strip especially Mtwara region have relative low risk for PWA, they live in fear of the unknown about their security. They said that the unexpected could strike any time and virtually from anywhere, since albino hunters were aware that people are not very conscious about the danger of having albinism in this area.

The informants in Dar es Salaam tended to concur on the reasons for high prevalence of discrimination of PWA in some areas than others in Tanzania. For example, they had similar perspectives on why the coastal region of Mtwara had fewer incidences involving PWA than the lake zone of Mwanza. They cited differences in traditional beliefs of different ethnic groups in Tanzania. One informant said:

> You know, in Tanzania there are many tribes and every tribe has its' beliefs and practices. You will find that there are some areas where they believe so much in witchcraft such that they must consult a witchdoctors and sorcerers for them to do anything. This is where the albinos are highly affected.

The informants observed that such characteristic were minimal Central Tanzania. One said; 'the things are not that bad in central Tanzania. Many tribes in that area are not so much into witchcraft, unlike the Lake region (*eneo la ziwa*), where many ethnic groups conservatively believe in witchcraft. The informant confirmed the association of the Sukuma people with witchcraft beliefs more than other groups in popular narratives in Tanzania, particularly in Mwanza. The respondents in Dar es Salaam indicated that persecution of PWA among the Nyaraba people, Wagogo, and Wanyaturu people of central Tanzania were almost unknown due to their almost faded witchcraft beliefs in the power of body parts from human beings and animals with unique traits. The informants attributed similar situation to northern region, the southern coastal areas, 'where these things and beliefs are not common'.

According to most of the informants, the control of discrimination, prejudice and persecution of PWA In the high risk areas reuired rigorous vigilance and community policing. This was being tried in Nyagunge and Nyigogo in Magu; Mwanza to weed out suspected hunters of PWA and protect their sorority in villages. Fear and anxiety had caused some parents to take their children with albinism for refuge in special schools like Buhangija (Shinyanga), Kabanga (Kigoma), Pongwe

(Tanga), Mitindo (Misungwi), Kitengule (Tabora), and Mugesa (Kagera). Other than creating sort of internally held refugees in their own country, people live in social isolation from their relatives and family. This practice separates the children with their biological parents and relatives fairly early in age, which may result in long-term psychological and emotional disorders in their developmental growth.

Besides, boarding facilities in sanctuary schools are an extra cost to these parents, who face enormous task in providing for the basics like the sun rays lotions, glasses and huts to the kids and treatment of skin cancers if some of them are affected. The challenge of abduction has in essence united the people leading to exceptional awareness on the plight of albinos in Tanzania, Eastern African region and the rest of the Africa continent. Today the international community and researchers are actively exploring the challenges of albinism beyond the security concerns to policy and proper integration of PWA in the mainstream development processes. This study indicates that achievement of this requires attention to the essential areas of livelihood vulnerability, strategic and practical needs of PWA.

4.2.6 Strategic and Practical needs

People with albinism in Tanzania have typical daily life experiences of other citizens. However, as already pointed out, their unmet strategic and practical needs in the context of unmitigated social exclusion often exacerbate their livelihood vulnerability and insecurity. The conditions of living for most PWA who participated in this ethnography were squalid, in either semi-permanent houses with *makuti* (coconut leaves) thatched roofs or urban dilapidated tenements. Mr. Jongelei, for example, lived in a tenement with open communal bathroom, with polythene partitions, in the peri-urban area of Mtwara area. This was reminiscent of the residence of two other PWA who were officials of their Tanzania Albino Society (TAS). They spent time in their TAS branch offices, trying to write aid proposals and hopeful wait for any news about the supply of the basic support items, such as lotions and medicines for PWA.

We visited Mr. Jongelei's home, situated in Mdenga; Mtwara township in the in late evening on April 20, 2011. Mosquitoes buzzed by in the dark room where we sat talking with Jongelei, his father and elder sister who lived with them after unsuccessful marriage. There were no mosquito nets and window screens as in many other *Makuti* structures in the area. We learnt that indeed Jongelei suspected that he had malaria as he lay on a mat. His father, too, lay on a mat, complaining of having malaria. They had no money, and the principal ethnographer had only 20, 000 Tanzania shillings, which he gave them to buy some medicines. They were very grateful for the offer from the 'visitor with blessings'. Jongelei's family epitomized the hand-to-mouth subsistence economy of many rural Tanzanians in Mtwara region. They tended maize, pumpkins, coconuts and a few other subsistence crops.

Four days earlier than the above encounter and observations, the principal ethnographer and his assistant interacted with a 17 year old boy with albinism. He was riding a bicycle in Mtwara town and agreed to talk to us. We sought to find out where he lived and he let us to where he stayed with his hosts; well wishers who accepted to house him. He had left his rural home in Masasi district, about 250 kilometers to Mtwara town. According to him, he had left his home with her aunt who later passed his in-law; his aunt's husband abandoned him. The local authorities entrusted him in the care of the well wishers who came from another district-Songea, but lived in Mtwara. He had to report to the Vigaeni village elder who supervised his care, every day to ensure his security. He tried to make a living by collecting sand along the road for sale. His hosts rented a room for him in the market place where an elderly woman lived with her middle ages female relative. This abandoned victim of albinism lived a hard life, that would remind one of the life of Bedinago, a teenage boy with albinism who lived with his parents in squalid conditions in Kisutu semi-urban village slum. In spite of the sensitivity of his skin and eyes to heat and sunlight, he struggled to contribute to family livelihood working as the operator of a locally fan for a village iron smelting kiln. The father had mixed feelings about perceived rescue of his son by the ethnographer whom he thought was a non-governmental organization agent seeking young PWA to take them to some haven.

The cases above give a glimpse into the ethnography of albinism and needs of the affected. They highlight the practical needs in any analysis of bio-cultural exclusion of PWA. These are albinism-related needs that PWA and their families as well as ethnographers can easily identify as they relate to living conditions. PWA and other actors can identify safe water, food, health care, cash income generation as the immediate needs they must meet. However, as pointed out earlier, the livelihood experiences of PWA in Tanzania are intertwined with generalized poverty of the citizenry, particularly in the rural areas, which should be addressed to ameliorate the society needs as a whole. Meeting the practical albinism related needs, such as provision of caps, long sleeved clothes, eye checkups and sunscreens are essential in order to improve their living conditions(see figure 3.1, chapter 3). However, in themselves, such measures may not change the prevailing livelihood vulnerability and fragility of the entire villages, families, or societies of which they are part. Therefore meeting of the practical needs among PWA should include a focus on strategic albinism related needs. That is, the needs that people identify due to their overall position in society manifesting inequality in resource distribution and over all culture of poverty. These relate to issues of economic and political power and control. The strategic needs in this regard would include equal opportunities and affirmative action in education and training, politics, employment, access to comprehensive healthcare for all and social participation in general.

An informant with albinism at UTTS in Dar es Salaam observed as shown in the excerpt below regarding the needs of PWA;

> The first thing is to educate the albinos themselves so that they can accept themselves the way they are. They have been created that way so they have to accept themselves. Secondly we enlighten them on the challenges that they face on a daily basis, such as suffering from cancer and related conditions such as poor eyesight, discrimination from the society…The discrimination makes them unable to contribute effectively to the economic activities. They lack the necessary capital; they cannot access loans and their families do not help them at all to establish themselves. It is like they were born and prepared to live in poverty. When they are able to realize this, they will be in a position to deal with whatever comes their way so as to live a better life…but on the health related issues they should know that skin cancer is caused by strong and direct sunrays. They should avoid working for long periods in the open sun. They should know that the sun is not good for them, if they can get the big hats to cover themselves they should do it, they should know which clothes to wear and if possible they should get the body lotion that protects their skin from the sun's rays. But above all it is the parents to take care of their children and enlighten them to take care of themselves.

Wide range of felt needs is depicted in the above informant's sentiments. He emphasizes ways of restoring self esteem, integrating the PWA in mainstream education and training system and initiating income generating activities. However, one of the essential areas of concern relates to the health care needs of PWA, which the next section pursues further.

4.2.7 Quest for sustainable health care services

PWA frequented the TAS and the association of people with disabilities offices near Raha Leo School in Mtwara Township. Similarly, the TAS office located in the premises of Ocean Road Cancer Institute in Dar es Salam was intermittently a beehive of PWA calling in and asking questions about any assistance. Most of the visitors checked to find out the status of the health care supplies. The personal care supplies were hardly available to the PWA who lived in remote rural areas in Masasi, Mwanza, Mtwara and even Dar es Salaam.

Mwalimu Ligombo, the class teacher of Chalolo, a primary school boy with albinism in Mtwara narrated about the perceived plight of her pupil. She said that he faced numerous challenges in his life due to his condition.

> First, the harsh environment he lives dictates the kind of life that he lives. If he is to succeed in school he needs to have a good program right from the home. The kind of life that he is living is not good at all. Due to his condition he is not able to understand some things in class. There are also some primary needs that he requires due to his condition but he does not get them (Mwalimu Ligombo, April 2011).

Feeling of difference affected the social well being of Chalolo as other PWA indicated in this ethnography. Perceived inferiority and exclusion impacts on constructions of the self and this has implications on emotional health. Due to this, Mwalimu Ligombo said:

> …he does not even want to answer questions in class…his skin has problems, he requires body lotion that he does not get, when the sun is hot it causes sun burns. There are things that they require so that they can live normal lives but they don't have them… He told me that he got the lotion once but he has used it and it got finished. When you buy him the other lotions they don't help much because they are not meant to protect him from the sun's rays. They are not the required lotions…This lotion, the original one cost 17 shillings per tube…A child like this one can use the tube for about 6 months but for an adult who can use it sparingly he can use it for about a year. The adult can just apply the cream on the areas that are in direct contact with the sun's rays...

Chalolo also had difficulties in reading on the board from far. Mwalimu Ligombo wished that there was an arrangement for reading glasses to help Chalolo.

Access to health care services for PWA was uneven during this ethnography as specialized services were limited. Some key informants mentioned services at the Mawenzi Hospital in Kilimanjaro Region. The hospital did not have special facility for handling or treating PWA. In addition, this hospital was too far from most of the regions with organized groups of PWA. As key informant indicated most of the health facilities, like Mawenzi in Kilimanjaro was not equipped to deal with the emerging public health problem of albinism in Tanzania. Kilimanjaro Christian Medical Centre (KCMC) has a promise with regard to health issues among PWA, which could be emulated in other regions in the ethnographic sites included in this study. The skin department caters for some of the skin care needs of persons with albinism. The centre operated mobile clinics on designated days (Tuesdays), depending on the number of PWA living in the (Kilimanjaro) region which they serve. KCMC endeavor to offer free health care services, including; protective clothing, wide brimmed hats long sleeved shirts, sunscreen lotions. The medical centre attempts to diagnose potentially cancerous conditions, such as, tumours, and skin ulcers and prescribe treatment. According to an informant who was familiar with KCMC activities, mosques and churches would be among the ideal places for creating awareness about available services for PWA.

4.3.1 Social and Cultural Policy for Rights and welfare

Most of the respondent and informants indicated their yearning for clear culture and social policy that would control social exclusion of and East African PWA, particularly in Tanzania. They emphasized cultural integration and awareness policy that would help avert the pervasive wrong perspectives about PWA (*mitazamo potofu kuhusu walemavu wa ngozi*). Indeed, such perspectives contributed to the trend among other citizens to deny PWA their citizenship rights, either wittingly or unwittingly.

Through their national association; the Tanzania Albino Society (TAS), Tanzanian PWA have lobby for establishment of better social policy that involves and recognizes them as a minority group among people with disabilities. Most of the study participants, particularly PWA believed that clear social and culture policy would ameliorate their lived. One informant said: '

> It is true that albinos have no life, especially here in the Southern region. I think the way you have come as researchers will help us a great deal. You should act as our voice and advocates. You should work to ensure that our lives are improved. When you come to a place like this, you find that like my brother here has a small business, you should help him to move from the level he is in to a higher level. That way he will be able to live like other people…. the albino should be facilitated to succeed; through education, the teacher should be very close to the student, that they should not just promote the student to the next class as normal routine in school…

Policies that would support economic empowerment of PWA were desired by all participants in this study. This would include improvement of working conditions as PWA cannot work for a long time in the sun need protective clothing and lotions to use. In a FGD in Mtwara, the participant point to the multidimensional social, economic and cultural issues affecting PWA. In this regard, comprehensive policies are required. In health care for instance, an informant opined that there should be special doctors to deal with people with albinism. He observed

> 'Albinism is a big problem because of in addition to albinism some of us are deaf or dumb. This makes t very hard for them to communicate since they use sign language. For sure the doctors just prescribe treatment using guesswork since they don't know what may be troubling the person. But a special doctor will be in a position to use sign language and will also be conversant with the needs of the albinos. That will help a great deal in the provision of healthcare to the disabled people.

Formulation of relevant policies would require both social and political will and commitment. Some PWA who participated in this study dismissed any claim of the existence and implementation of policy for social development and protection of the rights of their rights. Some argued that there seemed to be policy of albinism matters only during general election seasons.

> ‘They normally say that the disabled people should not be made to line up for a long time in the queues to vote... They should just be allowed to go immediately and vote so that they can leave. But in other areas, I have not seen such services. (This has not happened. It depends with the person. I just saw it the other day. I had gone to see the doctor, he came and saw me in the queue and he told me that I should go in and talk to him so that I can leave. This surprised me because ordinarily we are used to be treated just like the other people. I felt like I was being favoured but he said that that was his procedure. So I went in and talked to him and I left him attending the other patients. (Mwananchi, Mtwara, April 2011)

Mwananchi’s last sentiments point to the need for policy for affirmative action that would promote integration at the same time. For instance, a large majority of respondents among the PWA perceive exclusive schools for PWA to be a negative strategy for meeting their needs. Mwananchi clarified his view thus:

> This will not be right. Why is it not right? I think a disabled person just like a teacher cannot just work alone. He cannot work without cooperating with others. There is need to combine different ideas and talents so as to succeed. They can learn from each other. They also exchange ideas… Separating them will not help them at all. There will also be a problem when they finally interact with other people. That is in the school setting. But in the hospital it will be okay to give them priority. This is because if he stays for a long time in the hospital waiting to the doctor, he may suffer more due to his disability. If the sun becomes hot then this will affect his skin. So it will be better for him to see the doctor immediately, so that he can leave before the sun gets hot. He may not have an umbrella and may not have any protective clothing so he may be highly affected by the sun.

Policies on equitable access to available assistance also need to be pursued. Poor PWA living in remote areas hardly access health and social development assistance from the central and provincial governments as well as international non-governmental organizations, such Under The Same Sun (UTSS). Consider the assertion below:

> But this organization is not helping us at all. They have kept all the benefits in one area. They just work in Mwanza. But we here cannot appreciate the existence of this organization. They don’t appreciate our day to day challenges. They normally say that we have not been faced with the tragedies that have befallen our brothers in other areas. There is also the potential of business in other areas. They can easily get money in those areas and use it the way they want. All of them want to work in the Lake

> region. There is no potential for business in this southern region. They fear that when they come here they will have to assist without getting anything in return. Personally I feel that the organizations concerned don't think that there is a problem in Mtwara. "Under the Same Sun" only brought use calendars and nothing else… They don't even recognize that we exist. I think the person must have been drunk to bring the calendars here. That is pure discrimination. Although they have started with the calendars so we never know…

The assertion for the FGD excerpt conducted in Vigaeni village in Mtwara highlights more about perceived discrimination that compounds livelihood vulnerability among the PWA. One of the participants in the discussion noted: '…albinos have been discriminated in society for a long time, so they have also isolate themselves from the rest of society (*wamejinyanyapaa*)'… Besides the persistence with welfare and livelihood demands, existing national policies are hardly implemented. This leaves PWA almost entirely depended on well wishers and Non-governmental organizations like UTSS and religious institutions for their social and economic support.

In Kenya, the Kenya Albino Society (KAS) seeks to protect equal rights for PWA as a social, cultural and economic minority. The organization focuses on seeking for an all inclusive law that recognizes PWA as special group whose needs should be isolated from those of other people with disabilities. Although they often have low vision, they are not fully blind. Most of them are academically above average in school and college, but they rarely have the opportunity to access educational facilities. The new constitution in Kenya creates special seats in the senate and parliament for minority groups, one of which is the PWA. Recently a judge with albinism was appointed to the high court which was highly acknowledged by Kenyan and international society. But as a group, PWA continue to be marginalized in villages not only Tanzania but also in the rest of East Africa. In Tanzania, an overall movement of all associations for people with disabilities known as 'Shirika la Vyama Vya Walemavu Tanzania' (SHIVYAWATA) has the mandate to lobby and assist her members lead better lives. However, even with all these associations, PWA have little to be proud of in terms of social policy structures. As an official in TAS in Mwanza asserted:

> Policies which generalize albinism with other forms of disability are formulated. This denies us our basic and strategic needs. We do not have the means like other people to access essential facilities and basic livelihood means, such as, sunscreen lotions, caps, economic, education, security, employment and better living conditions).

Figure 4.1 Child with albinism, his sibling and mother with TAS official-Mikindani

CHAPTER FIVE

Summary, Conclusions and Recommendations

5.1 Introduction

This chapter presents a summary and brief discussion of key study findings. It then draws conclusions from the findings and present recommendations to guide policy framework development for the welfare of people with albinism in Tanzania and the East African region.

5.2 Summary of Findings

This study entailed ethnography of albinism rather than ethnography of albinos. It is a deviation from earlier studies that focused on albinos as a racial category. Ethnography of albinism in this case considers albinism as a universal human biological anomaly. However, their cultural beliefs, values and attitudes shape the responses to albinism and the experiences of persons with albinism. These aspects shape the lived experiences of PWA and their close social networks. The study results confirm that people with albinism experience multilayered intentional and unintentional discrimination. Both kinds of discrimination result from lack of information and awareness about the rights and personhood of PWA. This is the situation that could be aptly summarized in the words of many informants; *mitazamo potofu* (naïve or misguided perspectives).

This study found out that the fear and anxiety that grip People with Albinism (PWA) in Tanzania today is an ancient phenomenon embedded in belief systems passed from generation to generation. The persecution of PWA since 2007 is mere resurgence of this phenomenon, on a large scale. The fear of being attacked and the ambivalence about the personhood of PWA are intertwined and this further contributed to fear. The mythologies about albinism in both traditional and contemporary Tanzanian society as in the rest of Africa tend to dehumanize and depersonalize PWA. Both the present ethnography and ethnological data reviewed indicate such cross-cutting terminologies. These have far reaching consequences for the self esteem and sense of belonging, which in turn contribute to their low participation socio-economic activities that would improve their well-being. Ironically, deification of PWA is equally discriminative and contributes to their persecution. Bryceson, Jonsson and Sherrington (2010) similarly note that miners and magical functionaries (*Waganga*) in Mwanza have simultaneously marginalised, dehumanised, objectified and deified persons with albinism in the quest for mutually beneficial exchange and material rewards, yet many of the PWA are among the rural society's most vulnerable members.

Attacks, persecutions and killing of PWA are not confined to Tanzania. However, the main concentration of these activities is in Tanzania, which is apparently the hub, or the most visible context of extreme activities that have far-reaching implications for social, economic and emotional welfare of the PWA and their families. The fact that similar activities have been reported in Burundi, Kenya, and other parts of the East African Great Lakes region, central Africa, Southern Africa and even West Africa points to the fact that Tanzania epitomize only a part of the macro- ethnography site of albinism.

Perspectives on PWA include the cultural construction of mystical power associated with them. However belief that PWA just disappear and not die belie their tribulations, which are manifested in reports of uncanny mutilations. Therefore, stereotyping and livelihood issues that affect the PWA are apparent in both high risk areas of the northern regions of Mwanza and low risk coastal region of Southern Tanzania. Cultural beliefs about witchcraft and related superstitions are strongly interwoven within the assumption that albinos are a bad omen (source of bad luck) at birth and good luck (source of wealth) once they have survived extermination at birth.

All PWA and their families in Tanzania live in constant worry and anxiety since the widespread media reports about the insecurity facing persons affected by albinism. This fear and suspicion permeates both rural and urban sororities of PWA. The quest for financial capital drives the real or imaginary threat to people with albinism. Thus the PWA have increasingly been with commercial social labels such as money or 'deal'. Owing to the spate of killing of PWA, particularly in the Lake (Victoria) region, the public concern has focused on physical security. However, as the data in Southern Tanzania indicate, overemphasis of physical security has not always considered the concurrent strategic and practical needs of PWA as a minority group.

Witchcraft beliefs and superstitions that negatively affect the wellbeing of PWA are embedded in the local Tanzanian culture and livelihood issues. Notions and stereotypes of PWA need to be understood how these are embedded in individual socio-cultural context as it is with conceptualization of stigma (Goffman, 1963). Similarly, the livelihood contexts in Tanzania shape the experiences of discrimination among PWA and motivations of the perpetrators. This ethnography demonstrates that PWA in Tanzania are generally among the poorest of the poor due to their physical inabilities and inequitable access human resource development opportunities. Livelihood in areas with higher manifestations of the plight of PWA is fragile. However, PWA are unable to venture into income generating activities due to low levels of education and vocational training. On the other hand, several people with albinism have succeeded in demonstrating their potential for achievement like other citizens in education, art, civil service and professional development.

PWA are doubly excluded from normal life; that is, socially and biologically. This exclusion shapes their livelihood vulnerability and inability to meet their basic needs. As Bryceson, Jonsson and Sherrington (2010) noted**,** the carrier of human albinism is susceptible to skin cancer and blindness through exposure to the sun. Many PWA can lead active work lives, but others tend to be sheltered in the home, unable to participate in subsistence farming and other forms of livelihood activities. They struggle with seclusion, perceived disability both at home and community people have to work under the hot tropical sun.

Witchcraft and magico-religious beliefs associated with albinism aggravate fear and concerns about living conditions among PWA. The beliefs and superstitions elicit ambivalent responses with regard to their authenticity. Albino body parts are on high demand in face of the resurgent need for magical portions. These are particularly sought for prosperity in the face of generalized poverty and livelihood insecurity. Due to fear of facing legal consequences for murder hunters of body parts have resort to exhuming and cutting parts of the buried PWA, The onslaughts on people with albinism lead to leading to desperate measures of protecting them from attacks. In this regard, children with albinism, especially in Mwanza region are taken to boarding schools as their havens. The schools are considered physical refuge for children with albinism escaping the violence. The adult PWA on the other hand continues to live in fear and social isolation.

The key consequences of prejudice against PWA include inadequate social participation. This also results in inaccessibility to basic rights for personality and human development. Therefore, this study points to the need for effective information, education and communication programmes to raise community awareness about the integration of PWA in society.

A large proportion of the study participants held that they considered albinism as a disability. This is the 'disability of the skin' (*ulemavu wa ngozi*), as this is he most prominent aspect of albinism. Some PWA and their kin perceived albinism as a disability, in the sense of perceived anomaly, but not inability *per se*. This condition sets them apart from the larger society. The main perceived deficiency related inadequate resilience to sunlight and strenuous jobs. They need assistance in a number of areas and they are forced to 'walk under and sit shades all the time'. They cannot do most of the businesses under the hot sun. The special care that PWA need made them feel vulnerable and as people with disability. Contrary to what many people know, not all PWA in Tanzania have access to sunscreen lotions. The lotions are generally very expensive and the ordinary PWA would not afford it. The cheapest lotion cost about 20,000 – 30,000 Tanzanian shillings in Dar es Salaam. It is not available in remote areas for example in Mtwara; Southern Tanzania. Skin sensitivity, vision issues and psycho-social problems encountered by PWA present albinism as a public health problem which has not been accorded adequate attention in Tanzania and East Africa as a whole.

Persons with albinism, especially children pose significant care challenges. They may be perceived as a burden to the family. They need support to cope with the double biological and socio-cultural constraint of albinism. This contributed to the feeling that albinism makes one useless and wittingly segregated by other members of society. However this is rapidly changing in Tanzania with gradual community awareness about the personhood of PWA. They are gradually feeling integrated in society than before.

This study also found out that marital and sexuality issues contribute to livelihood vulnerability among PWA, especially the females. There was a high likelihood of single mothers with albinism than single fathers. None of the female PWA who had children were married. Apparently mothers were more responsible for their CWA than their fathers. More women without albinism would remain sustainably married to men PWA than men without albinism maintain marital relationship with female PWA. Men without albinism were more discriminative than the women with albinism. Arguably, sexual relationships between men without albinism and women with albinism were out of curiosity and beliefs about elimination or protection against HIV/AIDS. There is a popular belief that sexual encounter with PWA is a cure for HIV and AIDS, thus many albino women have been conceiving out of wedlock as men seek to get a cure for the disease or due to the curiosity about the sexuality of PWA. Single mothers with albinism had the burden of taking care of their children unsupported and some children with PWA had been left in the care of their grandparents. It was more likely to find a man with albinism married to women without albinism than women with albinism married to men without albinism.

This study found out that the plight of PWA in Tanzania was being addressed with reference to some nationally and international socio-cultural policies. The government of Tanzania has a policy to track down body parts dealers/traffickers with the aid of International Police. The government is committed to imposing heavy fines or jail terms for those involved in persecution of PWA. This policy is supported by Under The Same Sun (UTTS) which campaigns against killing of PWA in Tanzania. Under The Same Sun (UTSS) is the major non-governmental agency involved in advocacy for the rights of PWA in Tanzania. It provides socio-economic support, which some religious organizations and individuals supplement.

A policy of inclusion is visible in chances for PWA to be part of politics, civil service education, and human rights advocacy. Security committees were set to protect the welfare of PWA, especially children and youth. However, there was little effective policy framework to specifically address the plight of albinos as a special (minority) group. Most of the policies aggregate all people with disabilities, including albinism together. The measures taken against killings of PWA have not been adequate. In summary, stigmatization of PWA has short and long-term negative consequences on their lives. These are manifested lived experiences of social isolation, abject poverty, fright, and unemployment, among other indicators of social exclusion.

5.3 Conclusions

The decade 2007-2014 marks the climax of the spate of killings of people with albinism (PWA) in Tanzania. However, this is not only a problem in Tanzania, but also a social and public health problem in the rest of East Africa and beyond. Prejudice against African PWA has deep historical origins as they are conspicuous in an entirely black population. The physical environment aggravates the plight of PWA and the vulnerability they encounter due their condition. While it is important to ensure the physical security of PWA due to attacks motivated by magico-religious beliefs, the protection issues do not consider the criminal dimension of their persecution and violence they experience. In fact, there are undercurrents in the narratives that like the predicament of PWA to machinations that have political motives.

Efforts to surmount killings of PWA are highly significant for national and regional socio-economic development in East Africa. However, this has been over emphasized at the expense of other important aspects of livelihood. The physical protection of PWA for example should go hand in hand with programmes for socio-economic empowerment of individuals and families affected by albinism and the entire citizenry. PWA are discriminated upon in social life by not getting social partners for marriage and interaction. This is evident due to the labels they are given in society.

The persistence of beliefs and practices that are prejudicial to PWA and other people perceived as experiencing disability are indicative of low levels of awareness about human and minority rights. Very many factors are associated with the killing and violence against PWA, which need to be addressed. These factors are often epitomized in social labels, beliefs and superstitions associated with albinism. The narratives of PWA and those without the albinism traits indicate that strategies to protect those affected should begin with demystification of albinism. It is clear that albinism is not disability *per se*. It constitutes a trait that triggers special health care, emotional and livelihood needs. Therefore, PWA can be treated as a category of people that can be integrated in society through affirmative action and deconstruction of the chimera of their association with (benevolent and malevolent) mystical power, and pseudo-deification. People with albinism are not disabled. There perceived impairment could be easily corrected with the right materials and enable them live normal life and contribute fully to the development process of their countries. Protection materials; sunscreen lotions, spectacles to enhance vision, long sleeved shirts and huts are not readily available at the local market. However, these basic facilities are too extremely expensive for ordinary peasant families of PWA in East Africa.

PWA need to be integrated fully in the mainstream local socio-economic activities in the country to avoid making them dependent on the government, donor community and local people when they can provide for their destiny like other people in society. PWA are rarely absolved in the job market due to their limitations compared to other categories of the labour force.

On the over all, the plight of PWA in Tanzania is symptomatic of issues in the wider cultural, socio-economic and political contexts of albinism. In this sense, isolation of PWA into perceived havens does not constitute long-term or durable solution to the discrimination and violation of their human rights, which include the freedom of association. In the short time, PWA need to be convinced that they are fully secure and could engage in socio-economic activities for their growth and national building. Isolation of the PWA from the society to special schools is not a permanent solution to their insecurity problem and social development. It would lead to more psychological distress, suspicion and social exclusion.

East African Community (EAC) has not done enough to enact social and culture policy for integration of PWA and other minority groups in mainstream development processes. This is necessary for broader security and social protection systems for children and adults with albinism. However, Tanzania is much ahead of the other EAC and Common Market for Eastern and Southern Africa (COMESA) member states in initiatives for protection, sensitization and care of the PWA. In spite of this achievement, the policies that are specific to comprehensive social protection of PWA are either lacking or inadequate. While PWA have been recognized as a special group with unique practical and strategic needs, Tanzania and the rest of the countries in Eastern Africa lack the well grounded policy to address the key issues that affect them.

5.4.1 Way Forward: Study Participants' Views

PWA and other people who participated in this study had various perspectives on how to initiate sustainable social inclusion of people affected with albinism. A prominent theme was education of both PWA and the rest of the society. First, it would be necessary to educate PWA to accept themselves and their condition. This would enhance their self esteem and live with their congenital traits. Second, the study participants stressed the need to enlighten PWA on the daily life challenges of albinism. That is, sensitization on problems such as skin cancer, poor vision, discrimination and other physical limitations would help PWA to cope with their condition. The respondents were aware that discrimination makes PWA and their families unable to contribute effectively in activities that would ensure them economic income.

The education needs, according to key informants extend to the preparation of teachers. They need to understand the main challenges facing students with albinism, especially their poor eyesight and low self esteem. However, the study participants pointed out that the government has a central role in ensuring access to quality education by PWA. This has to include preparation of special font material for PWA and affirmative action in examinations and curriculum development. This includes special education curriculum to enable primary and high school teacher know how to deal with students with albinism. Such training was being implemented in Tanzania at the time of the data collection for this monograph. However, many post-school PWA did not support the policy for separate education institutions for PWA as a security measure. After the killings of PWA in Tanzania, several schools were set aside to admit more students with albinism. However, they were not meant to be schools for students with albinisms only, but they tended have more albinos than the normal skin colored students.

The likelihood of rejection of separate schools for PWA in Tanzania would result from two reasons. First, PWA and their families perceive commercialization of the schools through grant applications. Second, such schools would contribute to further social exclusion and discrimination. An official with TAS in Dar es Salaam observed:

> We have rejected such schools long time ago… If you recall clearly they had been proposed such schools when there were rampant killings of the albinos. They only wanted to use such schools for commercial purposes. We would hear that albinos are getting assistance which would have not been the case. By doing this we would already be discriminating against the albinos. It should be known that we were born in families where our parents have dark skin, our spouses also have dark skin and our children are also dark skinned. We have come from families that have dark skin. So, by having such schools we would be separated from the families that we had gotten used to. This would also create an impression that we as albinos are not supposed to live with and among other normal skin colored people. That is why we rejected these schools.

The lack of necessary financial, social and cultural capital also featured in discussion on the challenges to livelihood security among PWA and their families. The study participants suggested that both the PWA and their kin and governmental and non-governmental) development agencies need to devise easier ways for accessing loans. This would help them transform their lives from the culture of poverty and associated fatalistic worldview. It was observed that PWA and their families, especially in the rural areas may have internalized the perception that 'they were born and prepared to live in poverty'. PWA have the capacity to realize their social and economic potential. This would make them deal better with challenges of livelihood security, which the rest of the urban and rural poor in Tanzania and the rest of East Africa face.

Study participants took cognizance of albinism as a public health problem. In their view, this calls for initiatives to popularize self care among PWA as much as possible. This would entail knowledge about the effect of direct sunshine on the skin and eyesight of PWA. Thus PWA need to be encouraged to avoid working for long periods in the open sun. They should know that 'the sun is not good for them' and that they should seek any protective measure.

It would be necessary to inculcate courage among PWA and their families to 'fight for their rights'. Achievement of this depends on civic education for the PWA and other people who might be discriminated due to congenital limitations or differences. On the other hand, PWA argued that they need the guts to demand their education and health rights. They should also be involved in decision making where issues concerning them are been discussed and resolved. PWA are need to be proactive in their lives, but not passively wait for hand-outs from the government and donors. They need to develop confidence to enable them compete for resources and available training and employment opportunities.

All the participants in the present study expressed their pleas to policy makers to help improve the livelihood of PWA. The respondents believed that parliamentarians should lead in passing legislation would facilitate integration of people with perceived disabilities. According to the respondents, the laws should recognize the needs of PWA and other citizens with disabilities and involve them in decision and policy making in issues affecting their welfare. From this perspective, they admonished the government for the lack of programmes to tap the potential of each and every person, including PWA as a socio-cultural minority group. The respondents expressed the need to adopt the generalized policy documents, such as The Children's Act to address specific issues in living with albinism. The excerpt below is informative about the status of policy for the welfare of PWA and other minority groups in Tanzania and the rest of East Africa:

> The policies and laws are there, it is just a question of working on them. We thank the government, because it has tried to push for legislation that caters for and address the plight of each and every person. The only hurdle is the implementation. It takes quite a long time to implement them. So we can only hope that the implementation will be faster in future. Mr. Mwavyeo, Dar es Salaam, April 2011).

In sum, several suggestions were advanced regarding the way forward regarding the plight of PWA in Tanzania. First, there is a need to address the problem of livelihood fragility and socio-economic inequalities, which affect the lives of PWA and those who violate their rights. This would surmount all types of criminal activity, which affect individual with albinism and their families as they similarly affect other members of the society. The Community members need to play a more central role in protecting PWA in their midst through organized community policing and report any suspicious activities. More institutions should come up to assist this group of people including the governments not just the "Under The same Sun" (UTSS) as it is presently the case in Tanzania where this is the main players in assisting PWA.

5.4.2 Policy Recommendations

Local and international policy and legal instruments already exist in East Africa to facilitate the welfare and protection of people with disabilities, including PWA. The United Nations Convention on the Rights of Persons with Disabilities is the most outstanding framework that the United Republic of Tanzania can review and implement policy on PWA. While it is true that the question as whether albinism constitutes disability is still debatable, elevation of albinism as a form of disability on national development arena is necessary for comprehensive attention on the strategic and practical needs of the affected persons. This implies the imperative need to review the way PWA are labeled in national social development discourse. They are currently referred to as *Walemavu wa Ngozi* (people with disability/handicap of the skin). We argue that this is not a comprehensive term to help focus on the needs for holistic development of PWA as a bio-cultural minority.

The issues raised in this monograph indicate policy measures for the government of the United Republic of Tanzania and other actors concerned with the livelihood issues among PWA. Drawing on the *Ujamaa* and *Undugu* philosophies, a clear policy should be enacted for popular participation in social and physical protection of PWA and their families. This entails clear community policing frameworks that would supplement the efforts by the national police and human rights institutions involved in fighting all forms of atrocities against PWA and their kin.

There is need to establish East African Albino Association (EAAA) with chapters in all the EAC member states to coordinate and create awareness on albinism in all the states. It would also serve as a strategic power broker to campaign for the interests and fund-raise for their projects in the region and beyond. In relation to this Tanzania, which is apparently the epicenter of albinism persecutions, should lobby the EAC states need to enact a legal policy framework to prevent trafficking of PWA. This would also be a framework for negotiating to subsidization and tax exemptions on the health care resources for PWA. The resources, such as, sun screen lotions, ophthalmological care, caps and appropriate clothing are generally very expensive relative to socio-economic status of PWA and their families in rural Tanzania and the rest of East Africa.

Member states of the EAC should enforce an affirmative action in employment act, where all employers should have at least about 5% of their employees consist of PWA by law, where they have required skills for those positions. This would mitigate impoverishment among and make them self reliant. Children with Albinism (CWA) should not be isolated from the rest into special schools, but integrate them and sensitize the others to be their keepers in case of any threat. Tanzania and her counterparts in Eastern Africa should enact a policy framework to safeguard the interests of PWA and empower economically. They require initial capital to help the engage sustainable in Small Scale Investment Schemes (SCIS), which can to boost their livelihood security.

Country-wide and multilayered education is necessary to transform attitudes, and behaviors that are prejudicial to PWA. This should serve to deal with ignorance and mythologies that jeopardize the livelihood and social development opportunities among the PWA. This requires planning formal and informal education for all actors involved in influencing the lives of people with albinism. Efforts of organizations such as UTTS and TAS should be enhanced. The services offered through these organization and government departments should be made universally accessible and culturally relevant to all people with albinism in Tanzania. As this monograph has shown, PWA living in distant remote and rural villages in Tanzania seldom benefit from supplies and services provided by the government and non-governmental organizations. The services should strengthen and made available to PWA through the public health care system, schools, mosques and churches. The TAS offices all over Tanzania could perform the role of oversight and distribution centers for essential care facilities for the PWA in rural and urban areas alike.

Additionally policy makers need a framework for monitoring and evaluation of the instruments for the protection of PWA and other people with disabilities. This should also be in line with the need for justice and deterrence related to crime against PWA and their families. This should address unresolved cases of crime against PWA. As an example reports abound regarding no action or unexplained dismissal of cases involving grave-robbing crimes in Kagera region in 2008 and physical violence against PWA in other parts of Tanzania(Ntetema 2010). Civil society institutions in Tanzania, such as, Women's Legal Aid Centre (WLAC), Tanzania Women Lawyers Association (TWLA), Legal and Human Right Centre (LHRC), and Tanzania Gender

Networking Programme (TGNP) need to step up advocacy for the basic rights for people with disabilities, especially focusing on persecution of PWA. These institutions should also enhance public awareness about albinism and the rights of PWA in collaboration with their counterparts in other East African countries. Village security committees and community policing need strengthening through social participation and political will to root out violence against PWA as part of larger strategies to surmount all types of violence in society as a whole.

5.4.3 Recommendations for Further Research

More micro-ethnographies of albinism need to be carried out in Tanzania to ascertain the depth of issues in the daily lives of Persons with Albinism. As pointed out in this study, albinism is not unique to Tanzania or East Africa. It is a universal congenital human problem with health and social consequences. However, the responses to albinism and the actual experiences of the condition tend to vary with social, cultural, economic and political contexts. This means that more micro-ethnographies of albinism in different regions and districts in Tanzania would contribute to a better understanding of their daily life struggles with social exclusion. The quest for understanding of the social and cultural dimension of albinism as a biological and health issue in Tanzania can also benefit from a study of the cultural continuums in which the Tanzanian situation is embedded, as proposed in this ethnography. This would contribute positively to the quest for durable solutions to livelihood issues and social suffering associated with albinism.

Further macro-ethnographies of health and healthcare issues affecting PWA in Eastern Africa would contribute to mitigation their suffering. As envisaged in this study, it would be useful to undertake comparative ethnography on Witchcraft, superstitions and livelihood of people with albinism in Kenya, Uganda, Democratic

Republic of Congo, and Burundi. This would decipher the assumptions about the centrality of Tanzania in East Africa regarding activities that are prejudicial, oppressive, and discriminative of PWA. There is also need for gender sensitive studies aimed at programmes and initiatives for social protection of PWA and their families.

Interdisciplinary ethnography of albinism and minority groups is also necessary in Tanzania and the wider culture areas associated with these phenomena as shown in this study. Such studies should aim at documentation of the political, social and other cultural dimensions of the misery of people with albinism and their families. Present reports on PWA overemphasize physical protection against witch doctors and body parts hunters. This is done at the expense of many other gender-disaggregated strategic and practical needs not only among PWA, but also among other socio-cultural minority groups and people languishing abject poverty.

Figure 5.1: Typical shelter for PWA and Peasants in Tanzania

References

Allen, K, (2010), *Oppression through Omission: The Human Rights Case of Persons with Albinism in Uganda, Unpublished master thesis,* Beloit College, Beloit WI, School for International Training (SIT), Brattleboro, VT, USA

Aguilar M.J. (2006), *The Invention of Child Witches in the Democratic Republic of Congo: Social cleansing, religious commerce and the difficulties of being a parent in an urban culture*, Report by Save the Children. Available at: http://www.crin.org/docs/The_Invention_of_Child_Witches.pdf Date of retrieval: 30 November 2013.

Baker C. (2011), Representing "The Tribe of Ghosts": Stereotypes of albinism Emerging from Reports of Recent Attacks in Tanzania and Burundi, Paper presented at the 1st Global Conference by Inter-disciplinary net 12th -14th July 2011, available at http://www.inter-disciplinary.net/wp-content/uploads/2011/07/cbakerepaper.pdf. Accessed March, 24, 2014

Baker C. Lund P., Nyathi R. & Taylor, Julie (2010), the myths surrounding people With albinism in South Africa and Zimbabwe, *Journal of African Cultural Studies*, 22 (2): 169–181.

Baker, C., & Djatou M. (2007), Literary and anthropological perspectives on albinism. In *Crossing places: new research in African studies*, eds. C. Baker and Z. Norridge, 63–75. Newcastle: Cambridge Scholars Publishing.

Bonnerjea B. (1927), A *Dictionary of Superstitions And Mythology,* London: Folk Press Limited

Braathen S. H. (2005), *Albinism in Malawi: a qualitative study on attitudes and Beliefs,* Unpublished Master of Philosophy Thesis in International Community Health: Faculty of Medicine: University of Oslo

Biggs, J. (2004), *The Implications of social exclusion*: adopted from John Hills et al (2002) *Understanding Social Exclusion*, Oxford: Oxford University Press

Bogin, B. (1998), Milk and human development: an essay on the "milk hypothesis." *Antropologia Portuguesa* 15:23-36.

Bonner A. (2006), *Social Exclusion and the Way Out: An Individual and Community Response to Human Social Dysfunction*, England: John Wiley & Sons

Bryceson, F. D., Jønsson, J. B & Sherrington R. (2010), Miners' Magic: Artisanal

Mining, the Albino Fetish and Murder in Tanzania‘, *The Journal of Modern African Studies* 48:353-382.

Byrne, D. (2005), *Social exclusion,* Berkshire, England: Open University Press

Chambers, R., & Conway, G. (1991), *Sustainable Rural Livelihoods: Practical Concepts for the 21st Century*. Retrieved July 3, 2013, from http://www.smallstock.info/reference/IDS/dp296.pdf

Cimpric A. (2010), Children accused of witchcraft: An anthropological study of Contemporary practices in Africa‘. UNICEF Dakar, 2010. Available online: http://www.ecoi.net/file_upload/1930_1279627028_unicef-apr2010.pdf [Accessed December19 2013]

Coleman, L.M. (1997), '*Stigma; An Enigma Demystified'*, in (ed.) Lennard J. Davis; *The Disability Studies Reader* (Routledge, NY), pp. 216- 231.

Curran, A. S. (2011), *The Anatomy of Blackness: Science and Slavery in an Age of Enlightenment*, Baltimore, Maryland: The John Hopkins University Press.

Curran, A. S. (2009), Rethinking the Race History: The Role of the Albino in the French Enlightenment Life Sciences, *History and Theory*, 48: 151-179.

Dar es Salaam City Council (2004), *Dar es Salaam City profile*, Dar es Salaam: Dar es Salaam City council

Davis, L.J. (1997), '*Constructing Normalcy'*, in (ed.) Lennard J. Davis; *The Disability Studies Reader,* New York: Routledge,), pp. 9- 28.

Durand, P. (2010), *Serial Albino Killings in Sukumaland: Study on a Shifting Cultural Paradigm, available at http://www.africamission-mafr.org/Serial_Albinos_Killings_in_Sukumaland.pdf* accessed on March 26, 2014.

English, D.K. (2004), *Unnatural Selections: Eugenics in American Modernism and the Harlem Renaissance*, Chaper Hill& London: University of North Carolina Press.

Eriksson H. M. (2012), Witchcraft Belief and Accusations against Children in Sub-Saharan Africa: Human Rights in a World of Cultural Diversity, Unpublished Bachelor Thesis, Department of Political Science, Uppsala Universitet.

Ezeilo, B (1989), Psychological Aspects of Albinism: An Exploratory Study with Nigerian (Igbo) Albino Subjects. *Social Science and Medicine*. 9:1129-1131.

Farrell M & Corrine K. (2001), The Stigma of Congenital Abnormalities, in Eds. Mason T, Carlisle, C., Watkins C. & Whitehead E., *Stigma and Social Exclusion in Healthcare,* London& New York: Routledge, pg 51-62

Franzoi, S.L. (1996) *Social psychology*, London: Brown & Benchmark.

Garland, R. (1995) *The eye of the beholder: deformity and disability in the Graeco-Roman world*, London: Duckworth.

Goffman I. (1990), *The Presentation of Self in Everyday Life*, New York: Routledge

Goffman, E. (1997), '*Selections from Stigma'*, in (ed.) Lennard J. Davis; *The Disability Studies Reader (*Routledge, NY), pp. 203-215.

Green, M. (2003), *Priests, witches and power: Popular Christianity after mission in Southern Tanzania*, Cambridge: Cambridge University Press.

Hellum-Braathen S & Ingstad, B. (2006), Albinism in Malawi: Knowledge and Belief from an African setting', *Disability and Society*, 21: 599-611

Hong, E., H. Zeeb, & Repacholi M. (2006), Albinism in Africa as a public health Issue. *BMC Public Health,* 6: 210–16.

Ingstad, B. (1997), *Community-based rehabilitation in Botswana: The myth of the Hidden disabled*, Leviston: The Edwin Mellen Press.

Jayawickrama, N. (2002), *The Judicial Application of Human Rights Laws: National, Regional and International Jurisprudence*. Cambridge: Cambridge University Press.

Jolly, P & Plog T.G (1976), *Health and human color Abnormalities: in (ed.) Howard P;* Social biological factors influencing human color, Pritts and Sons, London, Pp. 142 -156

Kiishweko, O. (2008), J".K *Orders Crackdown to Stem Murder of Albinos,*accessed on Dec 28, 2013 at ttp://allafrica.com/stories/200810200901.html.

King R.A, Creel D, Cervenka J, *et al* (1980), Albinism in Nigeria with delineation of New Recessive Oculocutaneous Type. *Clinical Genetics*, 17:259-270.

Kromberg J.G and Jenkins T, 91982), Prevalence of Albinism in the South African Negro, *South African Medical Journal*, 61(11):383-6.

Kromberg J G, Zwane E. M, and Jenkins, T. (1987), The response of black mothers to the birth of an albino infant, *American Journal of the Diseases of Children*, 141(8):911-116.

Kromberg, J.G.R., D. Castle, E.M. Zwane, and T. Jenkins. (1989), Albinism and skin cancer in southern Africa. *Clinical Genetics* 36: 43–52.

Lapidos J. (2009) "How Many Albinos Are in Tanzania?" *Slate,*January 6, 2009.http://www.slate.com/articles/news_and_politics/explainer/2009/01/how_many_albinos_are_in_tanzania.html, accessed, March 22, 2014, 7:02:24 PM

Larson S (2011), Magic, Mutilation, and Murder: A Case for Granting Asylum to Tanzanian Nationals with Albinism, *Pace International Law Review*, 2 (Number 8):1-29.

Luande J., Henschke C. I. & Mohammed N. (1985), The Tanzanian Human Albino Skin, *Cancer*, 55(8):1823–1828

Lund, P.M. & R. Gaigher. (2002), 'A health intervention programme for children With albinism at a special school in South Africa', *Health Education Research*, 17 (3): 365- 372.

Lund, P.M. (2004), 'Health and education of children with albinism in Zimbabwe', *Health Education Research,* 16(1): 1- 7.

Lund, P.M. and R. Gaigher. (2006), 'A health intervention programme for children with albinism at a special school in South Africa', *Health Education Research*, 17(3):365- 372.

Lock, M. (1998), Menopause: lessons from anthropology. *Psychosomatic Medicine* 60:410-419.

Makulilo, E. B., (2011), *Albino Killings in Tanzania Illogical and Racism* http://sandiego.academia.edu/makulilo/Papers/155503/ALBINO-KILLINGS-IN-TANZANIA.

Madanipour, A., Cars, G. & Allen, J. (eds) (1998),. *Social Exclusion in European Cities*. London: Jessica Kingsley.

Mason, T. Carlisle C., Watkins C. & Whitehead, E. (2001), Introduction, In Mason, T *et al*. eds. *Stigma and Social Exclusion in Healthcare*, London: Routledge, Pg. 1-13

McElroy, A. (1990), Bicultural models in studies of human health and adaptation. *Medical Anthropology Quarterly* 4(3):143–265.

McLeod, T. (2010), *Albinism and the Contingencies of Stigma,* Unpublished Msc. Dissertation, London: University College of London.

McNeil D. G (1997). "Black, Yet White: A Hated Color in Zimbabwe." *New York*

Times Febraury 9, http://www.nytimes.com/1997/02/09/world/black-yet-white-a-hated-color-in-zimbabwe.html?pagewanted=all&src=pm , Accessed on March 23, 2014.

Michalko, R. (2002), *The Difference that Disability Makes* Philadelphia: Temple University Press.

Miguel, E. (2005), Poverty and Witch Killing, *Review of Economic Studies*, 72: 1153–1172

Mulemi B.A (2004), *Superstitions*, In Peek Philip and Kwesi Yankah (Eds) *African Folklore: An Encyclopedia***.** London: Routledge. Pp 446-460

National Organization for Albinism and Hypopigmentation (NOAH)-3, *African Americans with Albinism*, East Hampstead, USA. Available at: www.albinism.org National Organization for Albinism and Hypopigmentation (NOAH)-4, *Social and Emotional Aspects of Albinism*, East Hampstead, USA. Available at: www.albinism.org.

Ntetema, V. (2010), From the Courtroom: Murders to Hang, *Tunaweza Newsletter* Vol 1(September-December), Pg 8-12, Dar es Salaam: Under The Same Sun.

Ntinda, R. N. (2009), Customary practices and children with albinism in Namibia: A Constitutional challenge? In, Ruppel, O.C (ed.) *Children's Rights in Namibia,* Windhoek: Macmillan Education Namibia Pp 243-253.

Onyango Obbo (November, 28, 2008), Daily Nation United Nations/ General Assembly (2002) *World Programme of Action concerning Disabled Persons*, December 3rd 2002, A/RES/37/52.

Parker, J.N &Parker, PM. Eds. (2007), *Oculocutaneous Albinism: A Bibliography And Dictionary for Physicians, Patients, and Genome Researchers,* San Diego, CA: ICON Group International, Inc

_____________ (2003), *Albinism: A Medical Dictionary, Bibliography, and Annotated Research Guide to Internet References*, San Diego, CA: ICON Group International, Inc

Pernick, M, S. (1996), *The Black Stork: Eugenics and the Death of "Defective" Babies in American Medicine and Motion Pictures Since 1915*, Oxford: Oxford University Press.

Percy-Smith, (2000), Introduction: The Contours of Social Exclusion, In; Percy-Smith, J. (Ed). *Policy Responses to Social Exclusion: Towards Inclusion?* Milton Keynes: Open University Press. Pp 1-21

Pina-Cabral, J. de (2002), *Albinos Don't Die: Belief and Ethnicity in Mozambique*; Paper prepared for the Seminar; "The Process of Belief" organized by Fernando Gil, Pierre Livet and the author, the Ministry of Science and Technology, Portugal, July2002. https://www.academia.edu/3296916/Albinos_dont_die_Belief_and_Ethnicity_in_Mozambique , accessed on March 28 2014

Rebhun, L.A (2004), "Culture-Bound Syndromes", in Ember, Carol R. & Ember, Melvin, *Encyclopedia of Medical Anthropology: Health and Illness in the World's Cultures*, New York: Kluwer Academic/Plenum Publishers, pp. 319–327.

Reidpath, D.D., Chan, K.Y., Gifford, S.M. & Allotey, P. (2005), 'He hath the French Pox': Stigma, Social Value and Social Exclusion, *Sociology of Health & Illness,* 27(4): 468–489.

Reist M.T (2006), *Defiant Birth: Women Who Refuse Medical Eugenics* North Melbourne, Victoria: Spinifex Press Pty Ltd.

Robins, A.H (2005), *Biological perspectives on human pigmentation* Cambridge University Press.

Sievert, L.L. (2006), *Menopause: A Biocultural Perspective*, New Brunswick; Rutgers University Press.

Stensson, E. (2008), *The social stratification of albinos in Tanzania: a case study from Babati*, Södertörn University College; Institution of School of Life Sciences: Unpublished Bachelor's Thesis: Development and International Cooperation.

Stone, D. (2002), *Breeding Superman*: *Nietzsche, Race and Eugenics in Edwardian and Interwar Britain,* Liverpool: Liverpool University Press.

TAKNET (2009), The Plight of Albino in Tanzania: what should be done? *TAKNET Policy Brief Series No.4*, the Social and Economic Research Foundation.

Tebbe, N. (2007), "Witchcraft and Statecraft: Liberal Democracy in Africa," *Georgetown Law Journal* 96: 185-236.

United Republic of Tanzania (1997a), *Mwanza Region Socio-economic Profile*, Dae es salaam: Ministry of State Planning and Parastatal Reform. Available at http://www.tzonline.org/pdf/mwanza.pdf accessed March 25, 2014.

__________ (1997b), Mtwara Region Socio-Economic Profile, Dar Es Salaam: The

Planning Commission Dar es Salaam and Regional Commissioner's Office Mtwara. Available at http://www.tzonline.org/pdf/mwanza.pdf accessed March 25, 2014

__________ (2010), *Strategic Plan for 2010/11 – 2012/2013*, Dar es Salaam: DAR ES Salaam Regional Commissioner's Office.

UN General Assembly (1965). *International Convention on the Elimination of all Forms of Racial Discrimination*. Article 1 : resolution 2106 adopted by the General Assembly 21 December 1965.

Woolf C.M. & Grant R. B (1962), Albinism among the Hopi Indians in Arizona, *American Journal of Human Genetics*; 14: 391-400.

Woolf C. M. (1965), Albinism among Indians in Arizona and New Mexico, *American Journal of Human Genetics*, 17(1):23-35

Worthman, C. M. (1993), Bio-cultural Interactions in Human Development. In M. E. Pereira, and L. A. Fairbanks, eds., *Juvenile Primates: Life History, Development, and Behavior,* 339–358. New York: Oxford University Press.

Appendix I: Informal Interview/ Conversation Guide for Traditional 'Healers' [Waganga]

Gender___________

Age_______________

Region________________

Specialization_______________________

Time spent in career___________________

1. Tell me about past and current beliefs about albinos in this community? Are there any differences in beliefs in the past and contemporary societies?
2. Which special powers have witchdoctors and other healers associated with PWA over time?
3. Please tell me what you know about what people say about albino body parts and medical or magical portions.
4. Do people in this community still believe that albinos have supernatural powers? Do you know of any cases?
5. Did healers in the past use parts from albino bodies for medical and magical reasons? Explain what you consider extreme myths about albinos.
6. Why are albinos believed to be associated with mystical forces/powers?
7. Do you think some healers still seek albinos for medical and magical activities? Please explain your response.
8. What happened to albino infants in the past?
9. When are albinos thought to be sources of bad omen and good luck?
10. Tell me about narratives that you can recall in which success at present or in the past that were attributed to the powers that are believed to be inherent in albinism.
11. Why do you think there are more albinos in East Africa today than in the past?
12. Tell me what you know about the use of human parts in modern medicine.
13. Do you think traditional healers may be justified to use human parts in their activities?
14. If the use of some human parts in healing and welfare were legal, should the use of albino parts also be legalized?

15. What attributes of albinism contribute to success in health, well being and livelihood of other people?
16. What else would you like me to know about albinism, medical and magical beliefs among Tanzanians
17. Is it true that albino parts are more on demand in Tanzania than any other parts in Eastern Africa? [Probe also for reasons for either response].
18. Why does Tanzania seem the epicenter of reports regarding safety of albinos?

Appendix II: Informal Interview/ Conversation Guide for People with albinism and their relatives

Person with albinism/family member? _______________________________

Gender___________

Age_______________

Region________________

occupation_______________________

Level of formal education__________________________

1. Are there relatives who have albinism? And if yes who are these?
2. Are there reports about the albinism trait in your lineage?
3. Is it right to consider people with albinism as disabled/handicapped? Explain your response
4. How does albinism affect the daily lives of albinos and immediate families? Probe for narratives of stigma, isolation, discrimination.
5. How would you relate albino killings to witchcraft beliefs and superstitions?
6. How would you relate beliefs about albinos to economic deprivation in their families and the entire community?
7. Tell me about the descriptions, labels and names people often use to refer to PWA in this community? What do you think about these descriptions and what do they mean?
8. Do you think albinos have the potential to excel in social and economic sectors? Narrate some cases
9. How does living with albinism affect social interaction in this community?
10. Tell me about your daily life experiences owing to superstations and beliefs about the albinism trait in your family?
11. What powers do people say that albinos? Is this true in your view?
12. How do you think the lives of albinos in Tanzania and East Africa in general can be improved? What should the government, NGOs and general public do?
13. How best can albinos be helped to live a normal life as other members of the society?
14. What do you think about available strategies for protection and integration of albinos into the mainstream society in Tanzania today?

15. In view of 12 above, what are the strengths and weaknesses of the available initiatives?
16. How can cultural attitudes about albinos be change for improvement of their livelihoods?

Appendix III: Informal Interview/ Conversation Guide for Policy Makers and Implementers in the Government and NGOs.

Gender___________

Age_______________

Region________________

occupation_______________________

Level of formal education__________________________

Type of Agency [Government or NGO] _________________________________

1. How do prevailing beliefs and superstitions in this region affect the quality of life among PWA?
2. To what extent would you link albino hunting with economic resource deprivation in this region?
3. To what extent would you link albino hunting with social inequalities in this region?
4. Tell me about the implications of stigma for the livelihood of PWA and their families.
5. Tell me about the activities you engage in to improve the quality of life among PWA and their families.
6. Talk about the main limitations in your initiatives to advocate for the rights and security of albinos.
7. What challenges have you faced so far in attempts to address the special health care needs of PWA
8. How do you attempt to meet the rights of albinos to education and what challenges do you face?
9. Talk about current social and cultural policies that you are aware of, that exist to facilitate lives and integration of albinos in mainstream society, what are the constraints to the policies.
10. Tell be about the challenges to efforts to empower PWA economically and socially.
11. What do you think about official government policy to offer security and meet the needs of PWA?
12. Tell me about your assessment of legal efforts to deal with the perpetrators of crimes against the humanity of albinos in East Africa.
13. How do you think the lives of albinos in Tanzania and East Africa in general can be improved? What should the government, NGOs and general public do?
14. How best can albinos be helped to live a normal life as other members of the society?

15. What do you think about available strategies for protection and integration of albinos into the mainstream society in Tanzania today?
16. In view of 15 above, what are the strengths and weaknesses of the available initiatives?
17. How can cultural attitudes about albinos be change for improvement of their livelihoods?

Appendix IV: Informal Interview/ Conversation Guide for Key General Public Informants

Gender___________

Age_______________

Region________________

occupation_______________________

Level of formal education__________________________

1. Tell me about the myths, superstitions about albinos in the past and at present in this community.
2. What are the popular names given to people with albinism (explain the meanings and reasons linked to each label.
3. How do people react to the birth of an albino child in this society? Are the reactions changing? How was it in the past and now?
4. Would you say that albinos are treated in the same way as disabled people, such as the lame and blind? Explain….
5. What do you think about the intellectual and other capabilities of people with albinism?
6. Is it right to consider people with albinism as disabled/handicapped? Explain your response
7. How does albinism affect the daily lives of albinos and immediate families? Probe for narratives of stigma, isolation, discrimination.
8. How would you relate albino killings to witchcraft beliefs and superstitions?
9. How would you relate beliefs about albinos to economic deprivation in their families and the entire community?
10. Tell me about the descriptions, labels and names people often use to refer to PWA in this community? What do you think about these descriptions and what do they mean?
11. Do you think albinos have the potential to excel in social and economic sectors? Narrate some cases.
12. How does living with albinism affect social interaction in this community?
13. What powers do people say that albinos? Is this true in your view?

14. How do you think the lives of albinos in Tanzania and East Africa in general can be improved? What should the government, NGOs and general public do?
15. How best can albinos be helped to live a normal life as other members of the society?
16. What do you think about available strategies for protection and integration of albinos into the mainstream society in Tanzania today?
17. In view of 16 above, what are the strengths and weaknesses of the available initiatives?
18. How can cultural attitudes about albinos be change for improvement of their livelihoods?

Appendix V: Ethical considerations

Project title: Albinism, witchcraft and superstition in East Africa: Exploration of bio-cultural exclusion and livelihood vulnerability.

The principal and co-investigators are committed to upholding all ethical standards governing anthropological fieldwork. More specifically, the study focuses on a socio-cultural minority group whose rights and esteem should be protected during the fieldwork and research reporting. To begin with, respondents and informants in this research will participate voluntarily. The researchers will explain the research purpose and objectives to each respondent in order to obtain their informed consent to participate in the study. Each participant will be encouraged to feel free to withdraw from the study at any level if he or she would wish to do so. The study undertakes to respect the privacy and confidentiality of respondents and key informants.

The research is bound by the obligation to utilize the results in an appropriate fashion and disseminate the results through appropriate and timely activities. In addition, the researcher will be alert not to compromise anthropological ethics and appropriate demands of good citizenship among the participants or host-guest relations with the research subjects. At the end of the study, we will seek active contribution to shaping public or private sector actions and policies that may be as ethically justifiable in improving the livelihood of Albinos in East Africa. This is part of the desire to respectively refrain from ethical indifference with regard to the needs of the research subjects as we uphold ethical neutrality in our analysis. The study undertakes to respect the responsibility of researchers to the people with whom ethnographers work and whose lives and cultures they study. As envisaged in anthropological research ethics, this study subscribes to the following obligations:

- To avoid predictable harm that may result from the endeavour to develop knowledge that can lead to change in the quality of life of albinos,
- To respect the well-being, perspectives and esteem of the research subjects, for example avoiding discussions that they are uncomfortable about,
- To consult keenly with the affected individuals or groups, families and policy makers with regards to reporting and dissemination of the research findings. In this case, key actors in the study will have access to the draft results of the study before they are disseminated to education, advocacy and policy purposes,

The principal and co-investigator in this study will also do everything in their power to ensure that the present research does not harm the safety, dignity, or privacy of the study participants. They will determine in advance whether their hosts/providers of information wish to remain anonymous or receive recognition in the dissemination of the findings.

As aforementioned, the researchers will seek in advance the informed consent of persons being studied, providing information, owning or controlling access to material being studied. This study is open to further advice in relation to the requirements of other codes, laws, and ethics - for example on the recommendation of the Tanzania Commission for Science and Technology -relating to the researching and reporting on minority and vulnerable groups. The same consideration will be true for other countries in Eastern Africa where the researchers will conduct comparative ethnography on the research theme at a future date. Further, the principal and co-investigator in this study understand that the informed consent process is dynamic and continuous. This process is initiated during entry to study areas and continue through implementation by way of dialogue and negotiation with those studied. Informed consent, for the purposes of this study does not necessarily imply or require a particular written or signed form. Verbal consent following detailed explanation of the study will suffice. While the researchers may gain professionally from the study, they will not exploit individuals, groups or cultural materials. They recognize their debt to the societies in which they will work and their obligation to reciprocate the people studied in any possible appropriate way.

______________________ ____________________

Dr. Benson A. Mulemi **Date**
Principal investigator
Catholic university of Eastern Africa, (Kenya)

Appendix VI: Research Permit; P.I

Appendix VII: Research Permit; C.I

Appendix VIII: Letter to District Administrator

Appendix IX: Letter to District Administrator

Appendix X: Letter to District Administrator

Appendix XI: Ministry of Migration: Residence Permit

Appendix XII Introduction to Administrative Secretaries

Appendix XIII: Research Budget