TO EXAMINE THE PSYCHOSOCIAL CHALLENGES AND COPING STRATEGIES AMONG THE PERSONS WITH ALBINISM IN TANZANIA: THE CASE OF TEMEKE MUNICIPAL COUNCIL

SARAH RICHARD NZELWA

A DISSERTATION SUBMITTED IN PARTIAL FULFILLMENT OF THE REQUIREMENTS FOR THE DEGREE OF MASTERS IN SOCIAL WORK OF THE OPEN UNIVERSITY OF TANZANIA

2016

CERTIFICATION

The undersigned certifies that he has read and hereby recommends for acceptance by The Open University of Tanzania, a dissertation titled: **“To Examine the Psychosocial Challenges and Coping Strategies Among Persons with Albinism in Tanzania; A Case of Temeke Municipal Council”** in partial fulfillment of the requirements for the awards of Masters Degree of Social Work at the Open University of Tanzania.

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Prof. Rwegoshora Hosea

(Supervisor)

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DECLARATION

I, **Sarah Richard Nzelwa,** do hereby declare that this dissertation is of my own original and that it has not been presented and will not be presented to any other Institute of higher learning for a similar or any other degree award.

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Signature

……………………….…………

Date

DEDICATION

This dissertation is dedicated to my lovely husband Ambokile K. Mwakasungula who all the time encouraged me and supported the family in my absence. Special dedication is also given to my children who missed my attention while being tied up with both class and employer responsibilities. Also dedications should go to my Father Mr. Richard G. Nzelwa and my late Mother Damaris Richard Nzelwa who sent me to school and their efforts to make sure that I reach higher leaning Institute.

ACKNOWLEDGEMENT

The outcome of this dissertation is owed to several personal and institutional supports. An understanding of this generosity of the most collaborative contributions made by combined efforts:

My first gratitude should go to my research Supervisor Prof. Hosea Rwegoshora for his tireless efforts and constructive guidance towards the success of this work. I do much appreciate the advice on various technical issues and methodologies he extended to me throughout the study. Also my gratitude should go to the proposed Tanzania Association of Albinism (TAS) and their members who contributed their time that enabled me to gather information.

Altogether much appreciation goes also to Social Workers from Temeke Municipal Council for their endless cooperation and support during data collection. My sincere gratitude should also go to Tanzania Traditional Healers Association for their cooperation by distributing the questionnaire to its members at Temeke Office. I would like to thank my employer the Executive Director of Temeke Municipal Council for sponsoring my studies and my fellow colleagues for their support, cooperation and encouragement during my study.

I would like also to take this opportunity to express my sincere gratitude to Mr. Jonas Buhori and all Course Instructors for their guidance and assistance throughout the entire period of my study.

God bless you all for your cooperation.

ABSTRACT

This study attempted to examine the psychosocial challenges and the coping strategies among Persons with Albinism in Tanzania. The specific objectives based on challenges, attitudes, beliefs and coping strategies being employed by people with albinism. Study adopted quantitative and qualitative methods for data collection from Tanzania Association of Albinism, Traditional Healers Association, Social workers, parents and guardians who have children with albinism and People with Albinism through Self-administered questionnaire. However, the literature also discovered and indicated several effects, challenges and negative attitudes prevailing in the society in regard of Albinism and people with Albinism. The challenges range from structural to institutional in social services provision, human Rights violation and economic, emotional and psychological vulnerability of people with Albinism in Tanzania. The study found that there was positive significance relationship between society education, myths, traditions and beliefs that had keen to negative attitudes towards Albinism. It was noted that they also employ several coping strategies in absorbing the society neglecting situation. However, the effectiveness was found to be questionable and revealed to be temporary solving their psychosocial, emotional, depression and emotional effects. Furthermore, the study insisted on the education in abolition of cultural beliefs that contribute to the killings of people with albinism for dangerous myths and superstitions. Policy wise, the policy formulation should be participatory for effective implementation. There was a need of extensive research/surveys to determine how the People with Albinism cope with these psychosocial challenges associating to improve their coping strategies.

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AIDS	Acquired Immune Deficiency Syndrome
CWA	Children With Albinism
EAC	East African Community
FGD	Focus Group Discussion
HIV	Human Immune-Deficiency Virus
LHRC	Legal and Human Rights Centre
NGO	Non Governmental Organization
PWA	People With Albinism
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

CHAPTER ONE

BACKGROUND TO THE PROBLEM

1.1 Introduction

The chapter was elaborated on the background to the problem present the Albinism disability. A presentation on the statement of the problem, justification of the study, the objectives, research questions and finally the organization of the study.

1.2 Background to the Problem

Gronskov, E.K and Nielsen (2007) estimated that global prevalence rate of albinism is 1 in 17000. In Tanzania and other developing countries the occurrence rate of albinism has not been realistic due to lack of thorough baseline and gathering of data of PWA. Persons with albinism are particularly vulnerable in East Africa due to a combination of psychological, sociological and environmental factors highly repressing this group and violating their Human Rights. Most of the challenges faced by albinos are directly and indirectly caused by their medical conditions and psychological and sociological factors. Sometimes problems facing people with albinism may be associated with lack of comprehensive and accessible information on albinism currently availing (Lookingbill et al, 2005).

According to Charlotte et al, (2010), Albinism is one of several genetic disorders which prevent the body either partially or fully from producing melanin pigment, affecting the skin, eyes and hair, the most common form of albinism in Sub-Saharan Africans is Oculocutaneous albinism II (OCA2) characterized by little to no pigment in the skin, hair and eyes and is associated with vision problems. In line with

Haihambo & Lightfoot (2010) describe psychosocial impact as the effects resulted by environmental or biological factors on individual’s social and psychological traits.

This Albinism disability cause psychosocial effects on health, on human development, and mechanism, which accelerate in the progress of deficiencies in human behavior. This psychosocial effect is directly linked with psychological and social elements affecting the mental health, influencing personality traits, defense mechanisms, emotional cognitive status, and social and environmental factors promoting anxiety, trauma and stress (Ford, Howard & Oyebode, 2012). In the context of people with Albinism it has been highly affecting their personality, individual values, behavior trend and increase weaknesses in their psychological cognitive. This results to individual look for cognitive means to react to these environmental and social anxiety, trauma and stress in communicating with others (Rothman et al, 2008).

The psychosocial effects of Albinism is resulted to the trauma from being regarded as form of disability and regarded as worthlessness and useless in the society this is due to the beliefs, perceptions and myths on the causes of disability and society responses (Haihambo & Lightfoot 2010). In responding to it, people with Albinism develop various coping strategies including social avoidances, social isolation and sometimes develop defense mechanism strategies. Due to the increase psychosocial in last two decades there is a gradual rise of Albinism psychological adaptation and coping strategies, mechanisms of trauma and stress caused by the disability. Psychosocial impacts of Albinism is mostly contributed by the physiology of persons with albinism resulted to wrong myths and misconceptions due to lack of knowledge on the etiology of the condition. This enhances numerous psychosocial challenges that are embedded in the various socio-economic, environmental and political structures of the society (NOAH, 2004). This involves access to social services like education and health, which has been imperfect among persons with this disability due to stigma and discrimination. The situation is worse in Africa, where people with Albinism face stigma and discrimination which occur at institutional and structural levels as various socio-economic and political structures execute obstacles on persons with Albinism hence affecting their psychosocial development life (Kagore and Lund 2005).

However, due to the increased psychosocial difficulties the people with Albinism have employed various strategies in coping with this tense situation facing in their life. This involves engagement coping, which is aimed at dealing with the presented challenge or related emotions, and disengagement and avoidance coping strategies, which is focused at escaping the threat or related emotions (Mutasa, 2013). Disengagement coping strategies is always emotional focused, because it comprises an attempt to escape feelings of distress done by a person.

While Engagement coping strategies has been employed by people with Albinism as means of releasing psychosocial tensions that include problem-focused coping whereby a person developing certain forms of emotion-focused coping such as support seeking, emotion regulation and acceptance. Disengagement coping includes responses such as avoidance, physical and social withdrawal. For example, many of people with Albinism turned to religious beliefs and praying as coping strategy, this is in line with Durkheim (1915) and Marcus (2015) who pointed out that religion prays a critical role in the lives of the oppressed.

While the biological features of people with albinism (PWA) are unchangeable, the environmental and cultural factors and conditions that negatively affect their daily psychosocial well-being can be changed. Unfortunately Medical experts ‘natural’ scientists, socio-cultural policy makers and social workers have not succeeded in transforming prejudice, stigmatization and discrimination against persons with albinism in order to protect their fundamental human rights. It is out of such unsympathetic events in quality of life, the human rights approach to foster social changes born out of the social model of disability have been treasured by various governments to challenge the social oppression of persons with albinism (NOAH, 2005). In line with efforts of reducing the Albinos killings, the government and the Tanzania Albino Society (TAS) have agreed to form a committee that will include members from parties, traditional healers and all major stakeholders that will come up with a joint strategy to end the killings of albinos in the country.

1.3 Statement of the Problem

Persons with albinism are also normal human beings that should enjoy their lives just like any other person, however in recent years emerging killings and humiliations increased in Tanzania and other countries has been contrary to human rights (Larson, 2011). Persons with albinism are experiencing overwhelming of negative emotional impacts of stigma and cultural isolation. Mostly they are living in uncertain life leading to various psychosocial challenges that includes stereotyping, prejudice, stigma and discrimination leading to social exclusion and low self-esteem.

According to Land and Kagore (2005) stigmatization and discrimination among persons with Albinism have also resulted in emotions that include anger, depression and a guilty of conscience. However, due to these serious challenges, persons with Albinism forced to establish and utilize various coping strategies that array from seeking social support and releasing emotional tension through crying, avoidance, disengagement and engagement.

Moreover, still there is increased marginalization of people with Albinism in many societies in the world due slow change of the social, cultural and political conditions that contribute to further from mainstream societies. It also has witnessed government and media approaches to the plight of Persons with albinism in Tanzania and the rest of East Africa have always failed to prevent their murder, persecution, marginalization and social exclusion (Makulilo, 2011). It is against this background that the study seeks to investigate the psychosocial implications of albinism and explore the coping mechanisms used by them.

1.4 General Objective of the Study

The main objective of the study is to examine the psychosocial challenges and coping strategies among persons with albinism in Tanzania.

1.4.1 Specific Objectives

(i) To examine the society attitudes and beliefs towards the People with Albinism in Tanzania

(ii) To identify the psychosocial challenges that people with albinism face.

(iii) To find out the coping strategies being employed by people with albinism.

1.5 Research Questions

Based on the specific objectives, the study was guided by the following questions:

(i) What are the society's attitudes and beliefs towards People with Albinism?

(ii) What are the psychosocial challenges that people with albinism face?

(iii) What are the coping strategies being employed by people with albinism?

1.6 Significance of the Study

The study findings are critical as a basis for policy formulation in order to improve the quality of life of persons with albinism in the country. However the findings from the study are expected to be used for advocacy work around in an endeavor to improve albinos with psychosocial life.

In addition it is hoped that the explored coping strategies for persons with albinism can be useful to be adopted by various helping organizations, NGOs there by strengthening their programming. Moreover, the study will contribute to the body of knowledge on the psychosocial implications of disability specifically to people with albinism. This will be important for the researchers as stepping stone for further in-depth studies.

1.7 Organization of the Study

The study was organized in 5 chapters. Chapter 1 presents the introduction and background to the Problem. Chapter 2 deliberates on the theoretical framework and literature review on OCA and challenges associated with it. Chapter 3 articulates on the methodology employed in the study. Chapter 4 contains the data presentation, analysis and discussion of the findings. Lastly, chapter 5 presents the conclusions, summary and recommendations.

CHAPTER TWO

LITERATURE REVIEW

2.1 Introduction

This chapter reviews the relevant literature on albinism from a global perspective focusing on Albinism. The study discussed psychosocial challenges that include negative beliefs, myths, misconception and society attitudes that enhance stigmatization, discrimination and social exclusion of persons with albinism.

2.2 Definition of key terms

2.2.1 Albinism

Lund (2001) stated that albinism refers to a group of inherited conditions. Persons with albinism are characterized by the absence or reduced pigment in their eyes, skin or hair. Lund et al (2007) also pointed out that persons with albinism have inherited genes that do not make sufficient melanin, which is required for the full development of the retina which results in visual impairment.

2.2.2 Psychosocial

Nieman (2002) viewed psychosocial as a term that emphasizes the nexus between psychological aspects of the human experience and the social experience. Psychosocial aspects include the ‘biological, emotional, spiritual, cultural, social, mental and material aspects of experience which cannot necessarily be separated from one another’ (www.sacramentoasis.com).

2.2.3 Coping Strategies

Folkman, et al, (1986) defined coping as “constantly changing cognitive and behavioral efforts to manage specific external and/or internal demands that are appraised as taxing or exceeding the resources of the person’s stressful situation, independent of their values and effectiveness”

2.3 Theoretical Framework

2.3.1 Models of Disability

A model is a straightforward representation to help grasp the more complicated properties of a real life situation, or to clarify or interpret a phenomenon (Simpson and Cheasman, 2000). Simpson and Cheasman (2000) describe that understanding of disability is influenced by existing models, which are based on different assumptions. The medical and charity model is marked by the dependence of persons with disabilities and stereotypes associated with disability that trigger manifestations such as “pity, fear and patronizing attitudes behavior” (Munsaka, 2012). In addition the approach has clearly defined several social policies that reflect persons with disabilities as charity cases however, has been highly criticized. Reflecting to this the ongoing study rely on the social model of disability to explain the psychosocial implications of persons with albinism.

This model includes the charity, medical, social and bio psychosocial explaining disability. Oliver (1996) viewed the social model of disability as an important move from the medical model of disability that stresses on the functional limitations in the explanation of disability to the emphasis on how society structures restrict persons with disabilities.

On the same model Charlton (1998) pointed out that disabled persons are subjected to social oppression and negative social attitudes nevertheless of the socio-economic, political and religious environment of their society they live. The increased social oppression in turn increases individual, institutional and structural discrimination creating unfavorable social, environmental, and attitudinal barriers on persons with disabilities in our case is albinos.

In many societies most of the disabled persons are psychologically dominated by the society that originated their oppression. This social repression creates social exclusion of persons with albinism disabilities denying them sufficient and proper services. The social model of disability is founded upon the ground that disability is something imposed on impairments as a result of isolation and exclusion from the society (UPIAS 1976, Hong & Repacholi, 2006).

In this regard, Finkelstein (2001) argued that the social model of disability challenges the barriers that avert persons with disabilities from recognizing the same level of functioning as non-disabled persons due social structures work influences exclusion disabled people from full participation in society. In social work discipline out of its limitations, the social model of disability represents a significant achievement, both academically and politically, in understanding the relationship between disabled people and the larger society (Priestley, 2003).

It is the aim of the study to investigate the psychosocial implications of albinism permitting the discussion on the social model of disability, exposing how the society is socially excluding them and how they are coping with societal stereotyping, stigmatization and discrimination (Lund, 2005). Although the social model gave a new insight to the situation of disabled persons, it was criticized on certain aspects. It has been criticized for focusing on material disparity to elucidate the challenges faced by persons with disabilities.

2.3.2 Erikson's Psychosocial Development Theory

Erikson's model of psychosocial development is a very significant, highly regarded and meaningful concept. Life is a series of lessons and challenges, which help us grow. Erikson's wonderful theory helps to tell us why. Erikson believed that his psychosocial principle is genetically inevitable in shaping human development. Erikson's concept significantly incorporated cultural and social aspects, which is very accessible and obviously relevant to modern life, from several different perspectives, for understanding and explaining how society can influence the personality and behavior in people.

As such Erikson's theory is useful for teaching, parenting, self-awareness, managing and coaching, dealing with conflict, emotions and generally for understanding self and others. In fact Erickson theory reflecting how this people with Albinism challenges giving modern pressures on society, family and relationships – and the quest for personal development and fulfillment more relevant to their wellbeing.

Erikson's psychosocial theory basically states that people experience eight 'psychosocial crisis stages' which significantly affect each person's development and personality involving people with Albinism. This Theory refers to 'psychosocial crisis which is important in explaining people with Albinism internal emotional conflict developed due to social exclusion and marginalization caused by prejudice, discrimination and stigmatization. However, the theory describes this sort of crisis as an internal struggle or challenge which a person for our case are Albinos must negotiate and deal with (which is coping strategies) in order to grow and develop.

The challenges facing people with Albinism according to Erikson's 'psychosocial' based on psychological (or the root, 'psycho' relating to the mind, brain, personality, etc.) and from the society social relationships (external relationships and environment), both at the heart of Erikson's theory. The theory emphasize that in each stage involves a crisis of two opposing emotional forces or contrary dispositions. This reflects to each Albinos life crisis stage relates to a corresponding life stage and its inherent challenges facing them particularly the emotional and behavioral strengths which emerged from healthy progression through each crisis.

For example, in people with Albinism successfully coping and passing through each crisis involves healthy balance at crisis stage in theory (Lapidos, 2009). For example "Trust versus Mistrust" that reflecting, experiencing and growing through the crisis. Whereby 'Trust' involves of people life such as Albinism peoples future development and also experiencing and growing a suitable capacity for 'Mistrust' where appropriate, so as to cope with psychosocial challenges not to be hopelessly unrealistic or innocent, nor to be mistrustful of everything in their life.

From the theory described that a person including of the Albinism if passes unsuccessfully through a psychosocial crisis stage develops a tendency towards one or other of the opposing forces (either to the syntoonic or the dystonic, in Erikson's language), as a result, this failure becomes their behavioral tendency, or even a psychological or mental problem. Therefore, Erikson's ideas are very much related to real life and the way ordinary people think and wonder about things including albinism condition.

2.4 Albinism Overview

According to Kagore and Lund (2005) albinism is categorized into two major classes, which are Oculocutaneous albinism (OCA) and Ocular albinism (OA). Oculocutaneous albinism is marked by the lack of pigment in the hair, skin and eyes. Ocular albinism on the other hand has the same effects in the eye and the visual pathway as in oculocutaneous albinism; however, there is melanin activity hence no clinical significance in the pigmentation of the skin and hair (Oetting, Brillian and King, 1996). The etiology of albinism has been complicated because now and then the society perceives it around traditions and delusions. However, the situation of persons with Albinism is more glaring in Africa. Misconceptions on the etiology of albinism have geared some societies handling the condition as transmittable disease. Thus still in the society people believe that sharing the things such as utensils or physical contacts with a person with albinism also develop the condition (Lund et al, 2007).

According to Lund, Puri, Durham-Pierre, King, Brilliant (1997) stated that the existence of albinism differs considerably globally due to the dissimilar founder genes and the challenges related with differentiating diverse subcategories of albinism (www.ncbi.nlm.nih.gov). For example, in Tanzania the prevalence of albinism is more seen in central and Northern part. In South Africa occurrence rates of albinism differ among different tribes for example the Zulu and Tswana (Kagoreand 1995). This is contributed by certain ethnic groups, which has a higher prevalence as a result of traditional marriage patterns of consanguineous unions (Christianson, Howson and Modell, 2006).

According to Gronskov, Ek and Nielsen (2007) estimated that global occurrence rate of albinism was approximately 1 in 17,000, whereby Africa continent having the highest prevalence rates. Moreover, Christianson et al (2006) indicated that albinism prevalence rate is estimated at 1 per 40,000 in the majority populations though rare amongst African-Americans. Albinism is a hereditary genetic condition, which causes a total absence of pigmentation in the skin, hair and eyes. It affects one Tanzanian in 1,400 often as a result of inbreeding, experts say.

In the West, it affects just one person in 20,000 (TELEGRAPH, Tuesday 14 April 2015). While in the United State of America, the occurrence rate of albinism among whites is estimated at 1 in 36,000. In the isolated groups of the Hopi Indians in Arizona, of albinism rates are higher and estimated at 1 in 277 (McBride, Leppard, 2002).

In most of African countries and other developing countries institutional and structural discrimination towards albinism are found in government law and policies, the private sector and the social institutions like religion and marriage (Cruz-Inigo, Ladizinski & Sethi (2011). Kagore and Lund (2005) in their study also pointed out that Albinism is allied with numerous myths and misconceptions that prompt cases of teasing and name calling which affect levels of self-esteem among persons with the particular disability.

In this recent years being albino in the societies, has generated the new form of social markings which led to socially exclusion among persons with Albinism. These social markings stigma, prejudice and discrimination have been concreted by use of sneering and insulting language to identify persons with Albinism. For examples, in Tanzania the word "***Zeruzeru"*** used as social marking while in Zimbabwe the word ***'sope'*** and ***'jechwe'*** denoting something that is supernatural and occupied by bad spirits (www.africasia.com).

Moreover, stigmatization and discrimination have also been demonstrated in the marriage institution. For example, it has been common for women with albinism to find it difficult to establish marriage relationships because men avoid them for fear of getting a child with albinism.

In addition Mutasa, (2013) stated that such awful levels of ignorance shown in this form of misinformation, stereotypes, prejudice and superstition manifest in many societies has seriously negatively affecting the psychosocial well-being of persons with Albinism. This has been contrary to the realization 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.

According to Miller and Major (2000) stigma and discrimination are major sources of depression, guilt and anger among persons with albinism sufferings and embarrassment to persons with the condition and their parents. In most of the areas/societies negative attitudes and cultural beliefs towards persons with albinism especially children led to dropping from schools which affecting their future development career and productive employment in future.

The increasing of cultural beliefs in recent years in most Southern Sahara countries including Tanzania causes the mushroom of Albino killings hindering children going to schools and adult participation in production. NOAH (2005) stated that negative cultural beliefs have great consequences on the rights of persons with albinism. This includes the belief that albino body parts can be used in witchcraft to bring wealth and fortune hence, prompting the murder and mutilation of persons with the albinism condition.

In Tanzania Albinos are hunted down like animals and sold by their own families for £50,000: Tanzania's albinos sliced apart by witchdoctors who believe their body parts 'bring luck' in sick trade catalyzed by the need from country's leaders. Since collecting records started there total the attacks, there have been 74 killings and 59 survivors of attacks. Even the dead are not safe: 16 graves have been robbed (Flora, 2015). Due to the hunger for money it drives families to turn on their own loved ones with albinism in a trade allegedly.

Killings are associated with big misconceptions belief that albino’s body parts will bring a person wealth, or luck - and for that, people are willing to pay as much as $3,000 or $4,000 for a limb or as much as $75,000 - about £50,000 for the Albinos full set meaning the whole body (Flora, 2015). This has propelled frequent attacks to people with albinism cutting their limbs off - an act, which either leaves them severely mutilated, or dead. The combination of such misconceptions, beliefs and negative attitudes that creates stereotyping prejudice, stigmatization and discrimination to people with Albinism with poor governance has led to severe challenges in their psychosocial wellbeing.

2.5 Psychosocial Challenges Facing People with Albinism

Delusions and myths about persons with albinism in various countries of Africa, including Tanzania, have activated stereotyping, prejudice, stigmatization and discrimination towards them. Lund et al., (2007) defined stigma (the cognitive part) as a prejudice based on stereotypes and results in discrimination (the action part) hence they are frequently combined as stigma and discrimination. Mtetwa (2010) described that discrimination is an action based on stigma; a display of hostile behavior towards members of a group on account of their membership to that group which results in oppression hence, make difficult to claim rights (www.ok.org). Tanzania as other developing countries, still facing increasing stereotyping prejudice and stigmatization towards Albinism the reason behind involves lack of knowledge or ignorance, negative attitudes or prejudice and rejecting behavior prevailed in the society (Ntetema, 2010).

Thornicroft, (2006) postulated that stigma involves the insulting, social attitudes or cognitive beliefs towards persons with any disabilities grounded on social mark that primarily changes their confidence. Stigma towards persons with any disabilities has been common in most of underdeveloped countries holding various features that ranges from physical and social isolation from family, community, gossip, abuses, judging, accusing and attack. From this reflects that stigma and stereotyping prejudice diminishing their social status among people with Albinism as it distorts their inborn worth and dignity. In support Abraham et al, (2002) also emphasize that the society negative attitudes toward them, highly affects their self-worth resulting to uncertainty emotions such as anger, depression and guilt which has an impact on their health.

People with Albinism face discrimination actions. Throughout their ages they suffer the brunt of community segregation because people continue to regard them as social misfits. For example, from the time of birth are immediately exposed to discrimination from within their very own families. Child with Albinism is constantly exposed to inhuman treatment from an early age, which has lasting effects that cause low self-esteem (Abraham, et al, 2002).

However, the instance of children with albinism kept away from attending school has not been much officially documented, but many people demonstrated to the fact that it is unusual for persons with albinism to be given chances to go to school. With this increase of Albinos killings, parents are afraid to reveal that there is a person with albinism in the family fearing that they cannot afford to protect when going to schools (Ntinda, 2009). This preserves the system of education exclusion and leads to a high level of illiteracy among the albino population.

Hence the individual children with albinism who are getting the chances to go to school face additional forms of discrimination and are prevented from equal access to education, either directly or indirectly, from both peers and teachers. This has big impediment in their future gainful employment. The lack of broad sensitization about the condition of albinism and the prevalence of myths and misconceptions create an environment of fear and discrimination (Ntinda, 2009, Charlotte et al, 2010).

Moreover, though People with Albinism may engage in intercourse, when it comes to marriage, albinos are typically regarded as a “last resort” for men and women who cannot attract any other person (Munsaka, 2012). In some cases when albino woman is married, she may be a later wife in a polygamous marriage. Therefore, this reflects that there is still a psychosocial challenge in marriage institutions that discriminate the People with Albinism.

From the literature according to UN High Commissioner for Human Rights, Pillay (2013) indicates that, people living with albinism face several major challenges including fear of a fast growing business their body parts selling and their graves being dug up and despoiled. Due to misconceptions and myths, persons with albinism in many parts of Africa face stigma and various forms of discrimination and abuses/violations include:

Social stigma and insulting name calling leading to prejudice and discrimination to persons with albinism are largely seen as being incomplete. Many studies (Ntinda, 2008, Mutasa, 2013) concluded the presence of negative stigma attached to albinism as well as albinism is equated with, and categorized as a blemish, mark, stain, even disfigurement.

Gender based sexual violence to people with Albinism is common in southern African countries, including Zimbabwe, Swaziland, and South Africa. Ceremonial desecration and rape of girls and women with albinism have been observed in. According to Navy Pillay (2013) it is associated with the myth that having sex with a woman with albinism can cure HIV/AIDS has motivated this form of violence. The violence shocking trend has left the victims contracting HIV which complicates their health and psychosocial condition. Therefore, defilement and rape are violations on the dignity of a woman and an abuse of the rights to safety and security of the person (Charlotte et al, 2010)

Killings and harvesting of body organs has been currently increasing among persons with albinism in east and southern Africa, especially in Tanzania. The killings are done in order to harvest body parts used in making of charms by traditional witch doctors believing hair, genitals, limbs, breasts, fingers, the tongue and blood make strong magic portions which sell for more (Navy, 2013; Stensson, 2008).

Lack of appropriate medical attention in treating lack of melanin pigment and health problems of the skin and vision has been keeping them at higher skin cancer risk. Persons with albinism are affected by ultra violet rays from the sun, which cause scratches. To lessen the effects of the sun, persons with albinism need to apply special jelly, sunscreens, wear hats and use special sunglasses, which are costly and in most rural areas are unavailable (Navy, 2013).

Discrimination in employment and education systems has continued. Still there is a belief that persons with albinism are incapable or are a burden; being obstacle for them to join with education system hence, rejected from employment by both private employers and some public institutions due to their condition. Other challenge involves attacks on persons protecting/defending persons with albinism especially family members taking care of them have been harmed or even killed. Cases have been recorded from Tanzania to Burundi where attackers brutalized family members of persons with albinism. A Tanzanian journalist, Vicky Ntetema, (also the current Executive Director of Under the Same Sun), was also threatened for working to unravel the killings of persons with albinism in Tanzania (Twaweza Newsletter, 2013).

According to Ntinda (2009), in Africa many people are affected by albinism, but people with albinism in Africa have distinctive appearance, which has a powerful impact on their lives from birth to death. This based traditional explanation concentrate on fortune of illness or deviance rather than on biomedical explanations, different appearances impact on their socialization.

Other challenges include social and cultural challenges inhibited by discrimination, or even fear and violence. African albinos endure segregation and threat throughout their lives, and in some cases they are killed after birth to avoid discrimination (Masakhwe, 2009).

2.6 Perceived Societal Beliefs and Attitudes

In most rural areas in Africa and Tanzania in particular bearing children with albinism has been a curse or retaliation for something wrong done before or as being a victim of witchcraft in the family (Waugh, 2005). Khan, (2005) argue that traditional beliefs and practices are very wrong and are very harmful to the emotional, physical and psychological state of both children and adults with albinism. However, in recent decades we have witnessed the growing of traditional beliefs of fortune associated with Albinos' body parts.

Cultural changes and transformation of attitudes and beliefs that dehumanize people with Albinism can help them to avoid some of the hardships they face, which are not necessary the outcomes of albinism. Mystical beliefs, stigma and discrimination of people with Albinism have diminished in many non-African culture areas, is contrary to what many people know the real situation prevailing which tend to deny people with Albinism full personhood and humanity (Waugh, 2005). Thus the phenomenon of social cultural exclusion and marginalization of albinism is based on the cultural construction of biological fitness, forms of physical deficiencies and abnormalities.

Traditional African beliefs and cultural attitudes about albinos and their families contribute further to their social exclusion. Kidnapping and murder of albinos for portions of good fortune, witchcraft, magic 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 (Makulilo, 2011).

However, in some areas when African albinos survive, baby born due to superstitious negative beliefs and fear of evil make local people link to the birth of a person with albinism, they soon become victims to those who believe that albinism epitomize mystical power that can facilitate different forms of prosperity or success. However, King, et al, (2005), pointed out that the ways in which present problems facing people with Albinism is deeply embedded in indigenous cultural attitudes, norms and beliefs among ethnic Tanzanians and related to African societies.

2.7 Social Reasons for the Killing of Persons with Albinism

Increasing killings of persons with albinism in East and Southern Africa, especially in Tanzania, have necessitated the governments to craft protection measures to ensure that their rights and dignity are fulfilled (Lugungulo & Amri 2009). Though persons with albinism are found all over the world, there is still lack of knowledge on its etiology include ritual killings (www.albinism.org.uk, Makulilo, 2011).

The belief that body parts from people with Albinism have mystical power has flourished in Eastern Africa over time. This contributes to expectations of a great deal of fortune by body part traffickers. Traditional beliefs and inclination to the authority of local healers (witch doctors) in explaining sources of hardships or misfortunes fortify the vulnerability of people with albinism today.

Since 2007, Tanzanians have witnessed a wave of albino killings with parts of their bodies being brutally chopped off. This evil is driven by the belief that albinos’ body parts possess magical powers capable of bringing riches (Makulilo, 2011). NOAH (2005) highlighted that the murder and disfigurement of persons with albinism is backed by traditional healers to create charms using body parts. In Tanzania this is widely spread that charms mixed with body parts of persons with albinism; especially the hair, breasts, fingers, tongue, genitals, limbs, and blood create a strong magic fortune (NOAH, 2005).

In Tanzania albino body parts sell for around $600 in Tanzania, with a whole body fetching $75,000, according to the UN, (2014), Albino killings prevalence's rise during election times as demand increases for magical helpings by politicians seeking election or re-election (www.albinismmfoundationea.com). Moreover, Mtetwa (2010) he also pointed out that persons with albinism are perceived to have supernatural powers that lead to be victims of ritual killings.

However, killing trend has also affects southern African countries and other parts of Africa. Killings have been reported in Kenya, Uganda, Congo and Burundi possibly to sell the organs in Tanzania (Allen, 2010). The trend has now hit southern African countries with killings reported in Swaziland and Zimbabwe. Similar cases have been reported in Mali, West Africa. Also, people in Benin believe that blood of persons with albinism has magical properties and that it brings prosperity and luck.

The fingers of persons with albinism are worn on necklaces around people's necks as lucky charm (www.albinism.org.uk). Lund and Gaigher (2002) these killings are being associated with a belief that the blood of persons with albinism holds supernatural powers that bring prosperity and good luck. The situation is worse in Central Africa where they are regarded as sacrificial lambs. Their Body parts such as fingers are also used to make charms (www.albinism.org.uk). The demand for body parts of persons with albinism has resulted in callous attacks done against them (www.albinismmfoundationea.com).

The other killings of Albinos have been observed in infants with albinism, some communities believe that they do not live long causing the heartless killing of infants with albinism at birth which is against to their constitutional right to life (Allen, 2010, www.albinism.org.uk). In addition, there is a prevailing death myth associated with the belief that people with albinism do not die a natural death only vanish in the bush, the myth is extensively perceived in South Africa (King, et al, 2005, Lund and Gaigher, 2002). Also some people possess other mysterious myths like the belief that if someone emotionally abuses a person with Albinism in turn will give birth to an Albino baby.

2.8 Psychosocial Coping Strategies

Despite of a number of measures at both international and national, levels have been taken to address the problem, still psychological and social marginalization of people with Albinism have been facing difficulties (King, et al, 2005), Internationally the International Police (Interpol) have been involved to manhunt the suspected human traffickers operating in other countries. Furthermore the work of renowned campaigners like the Canadian albino businessman Peter Ash (with the Under the *Same Sun programme*) have been initiated to fight the killings of albinos.

Furthermore, government implemented legal measures such as the banning of witchdoctors’ operations; directives to the regional security committees to protect albinos. Moreover, government initiated a secret ballot system for identifying those alleged of dealing in human body parts and provision of mobile phones to albinos to quickly pass on information to investigators (Makulilo, 2012).

This failure of all measures to address the challenges facing people with Albinism has meant that the victims have to cope with situations in the society they live by creating and employing various strategies in coping. In the study by Mutasa (2013), identified that for disability cope with the psychosocial problems due to their conditions, the mostly practice engagement and disengagement and avoidance strategies. This has important in for emotion regulation, cognitive-behavioral as well as tuning the brain's sensitivity to stress.

(Hellum-Braathen at al., 2006), Rholes at al., 1999) research examining albinism issue by investigating whether adult's albinism with high levels of attachment avoidance show patterns of sympathetic nervous system reactivity in repressive coping. This indicates that the emotion-minimizing strategies of avoidant individuals do not successfully lessen Albinism psychosocial reactivity. For example, Summers (2009), found that avoidant individuals showed significant heart-rate reactivity to an experimental anger stimulation, despite the fact that they did not report high anger.

The avoidance coping strategies is just escaping the threat or related emotions (Meaney, 2001) People with Albinism are always anxiously attached, thus individuals tend to show heightened and continued negative emotionality, in other way avoidant attached to individuals tend to minimize, suppress, or dismiss negative emotions and feelings (Allen, Moore, Kuperminc, & Bell, 1998; Fraley Shaver, 1997).

Disengagement coping strategy is always emotional focused, because it comprises an attempt to escape feelings of distress done by a person. Feeney, (1999) describe that for avoidant individuals, one might presumption that their tempered negative emotionality is complemented by similarly tempered physiological reactivity, protecting their bodies from the harmful effects of continued stress reactivity over time.

This is regular with the concept that the emotion regulation strategies of avoidant individuals strategies are preemptive, involving disengagement of attention from distressing experiences before negative affect has been encoded and experienced (both subjectively and physiologically). According to Kiecolt-Glaser et al., (2002) in avoidant the preemptive and dissociative perspectives is that avoidant individuals might use both strategies, only under different conditions. Preemptive strategies can be the ‘first line of defense,’ but when intentional negative emotions are particularly intense and/or continued, avoidant individuals might be forced to rely on repressive coping to minimize distress.

In addition, engagement coping strategies have been employed by people with Albinism as means of releasing psychosocial tensions that includes problem-focused coping whereby a person reaction focused coping such as support seeking, emotion regulation and acceptance. For example physical and social withdrawal many of people with Albinism turned to religious beliefs and praying as coping strategy (Treloar, 2000).

2.9 Research Gap

The undergoing research was looking in identifying the psychosocial challenges facing people with Albinism in their daily life linked to how they cope with it in Tanzanian context. Thus, although many studies concentrate with the adverse effects of the challenges facing people with albinism while there is a gap in how the individuals PWAs specifically cope with these psychosocial problems. In this Study big emphasize has been done in the institutional and structural measures in addressing the effects of social inclusion, lessened dignity due to beliefs misconception, stigmatization and discrimination.

2.11 Conceptual framework

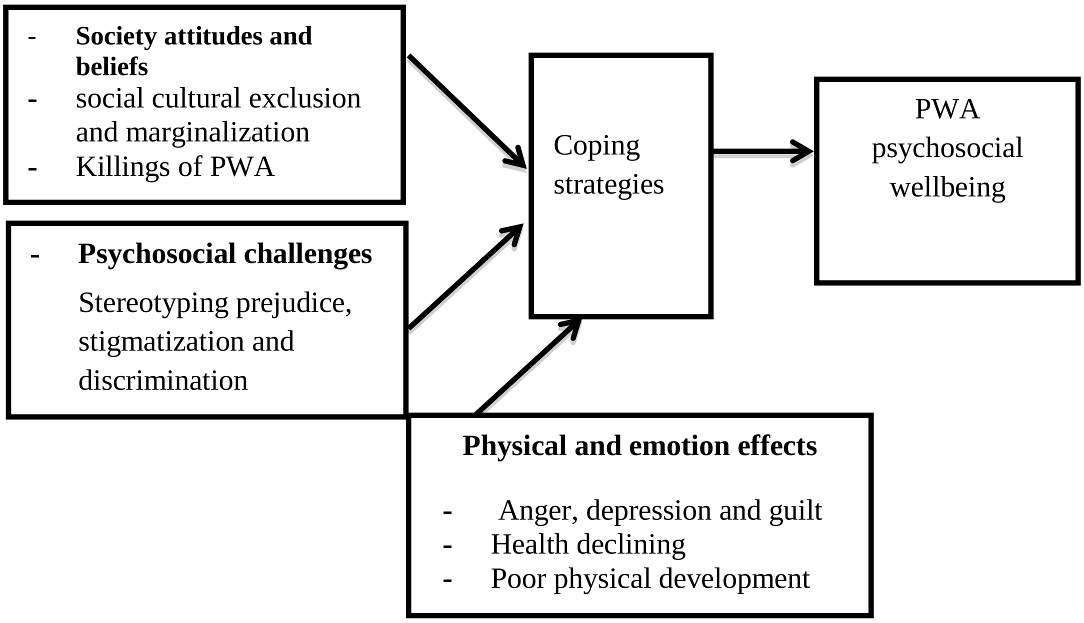

Figure 2.1: Conceptual Framework

Source: Researcher Designing (2015)

From the conceptual framework indicates that negative attitudes toward PWA highly affect their self-worth resulting creating uncertainty emotions such as anger, depression and guilt, which have an impact on their health and physical development. This is due to many psychological effects they encountered; this includes Stereotyping, prejudice, stigmatization, discrimination, etc. The society belief and negative attitudes have been completely resulting to social cultural exclusion and marginalization of the PWA. However, PWA develop various coping strategies to cope with these unpleasant psychosocial situations that include engagement and disengagement coping strategies, Avoidance coping strategies, Family/self-help group formation and Isolation coping strategies.

2.11 Conclusion

This chapter has deliberated the key issues concerning the society and stigmatization of albinos particularly the social stereotyping, stigmatization and discrimination. Issues of gender based violence against persons with albinism and killings were also covered during the discussion. The literature above shows that persons with albinism within the African context are psychosocially teased from living framework to grave.

Due to the psychosocial difficulties, their self-esteem tends to be low and the apparent societal attitudes towards them are highly negative as well. The social model of disability and the self-esteem and Erickson psychosocial theory have explained the social aspects of albinism and how persons with the albinism condition value themselves. Moreover, the failure of the system in helping them to cope has resulted to individual coping strategies emerging such as engagement, disengagement and avoidance. Through which repressive, preempt and disassociation techniques were used.

CHAPTER THREE

RESEARCH METHODOLOGY

3.1 Introduction

This chapter presents the research methodology. It has the following sub-sections, research approach, research design, study area and significance of the study, population, sampling, sample size and its justification, sampling procedures, data recording. Furthermore, it describes the data collection methods, research tools, data analysis, presentation methods employed by the study and ethical implications.

3.2 Research Approach

According to Kothari (2004) research approach referred to an integrated set of principles and general procedural guideline. Basing on the epistemological position, there are two types of approaches namely, quantitative research approach and qualitative research approach. Therefore, this study applied mixed methods of data collection, analysis and interpretation.

3.3 Research Design

Kothari (2008) defines research design as the arrangement of conditions for the collection and analysis of data in a manner that aims to combine relevance to the study purpose with economy in procedures. The research designs adopted is cross-sectional adopting both qualitative and quantitative approaches. (Kombo & Tromp, 2006) Comment that the cross-sectional design is referred when data are collected at once in a specified time period and were given equal weight.

The research design selected based on the following reasons; it is relatively inexpensive and takes up little time to conduct; secondly, can estimate prevalence of outcome of interest because sample is usually taken from the whole population. Moreover, many outcomes and risk factors can be assessed while collecting a lot of information about potential risk factors in a cross-sectional study. Lastly, design is useful in studies with descriptive nature.

3.4 Area of Study

The study was conducted at Temeke Municipal Council. According to the 2012 Census report 1,368,881 total population of Temeke of whom 669,056 were male and 699,825 females with an estimated growth rate of 6.6% per year and area of 786.5 square kilometers (Source 2012 Population census). Not only that but also the Municipal have potential number of people with Albinism reached 409, whereby 135 were Females, 217 were Men and 57 were Children (source: Temeke Municipal Council, 2014).

The research was conducted in Dar es Salaam city surveying members at the TAS (the Tanzania Albino Society) and Social workers from Temeke Municipal Council. The Tanzania Albino Society was chosen because it is easy for data collection from members and due to financial constraints and time limitations facing the area would be suitable for effectiveness of the study. The Temeke Municipal Council was selected because of the researcher’s limited financial resources and time constraints. Also Temeke Municipal is highly populated.

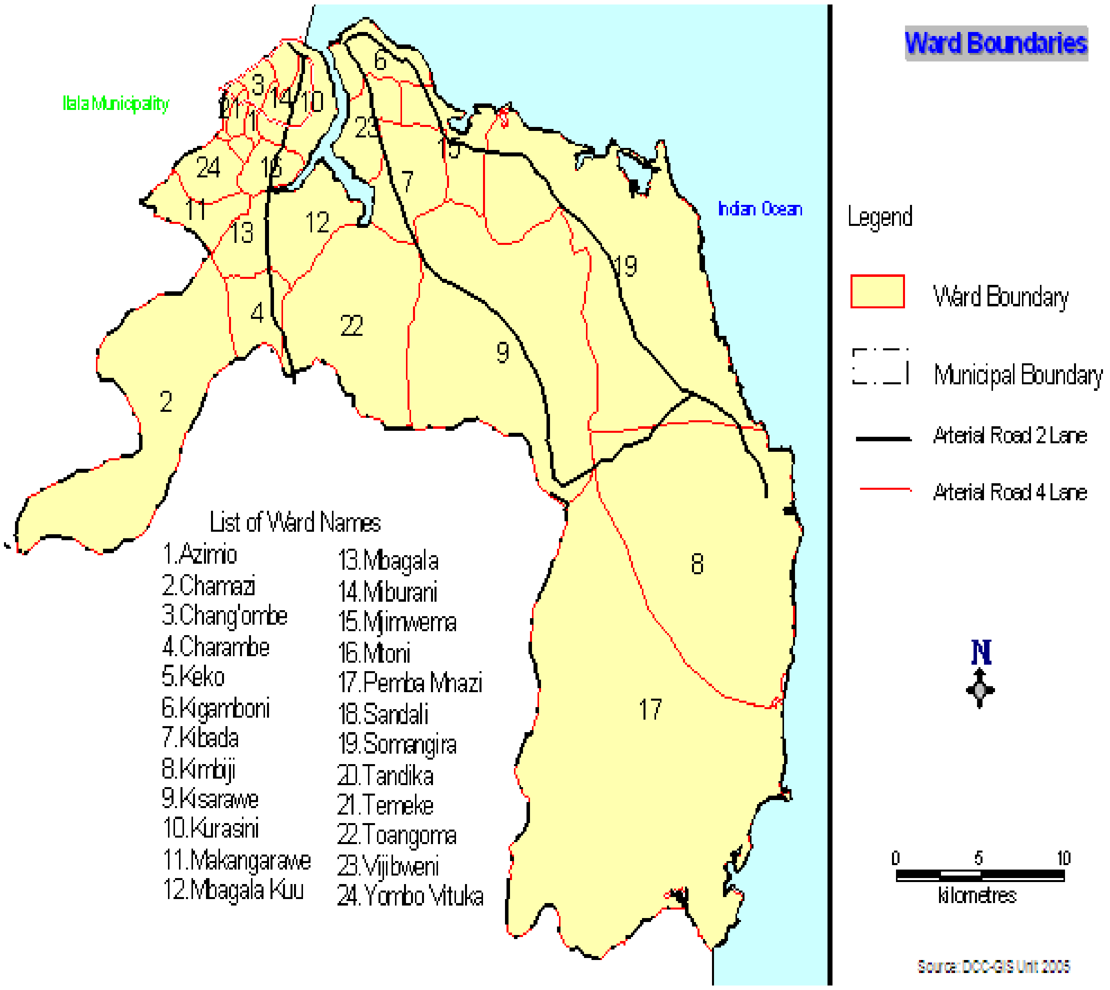

Figure 3.1: Map showing Different Areas in Temeke Municipality

Source: Google (2015)

3.5 Population of the Study

Population of study whereby the sample size drawn included different categories and depending on their albinism conditions and potential roles in albinism issues in Tanzania. Their inclusion in the study is as follows:

People with Albinism are the key participants as the direct victims of the psychosocial challenges happening due to their conditions. However, due to the difficulties they face, are the ones who develop the coping strategies that also being the theme of the study.

Traditional healers are the part and parcel of the emerging misconception beliefs among dealers using the albino’s body parts for making charms for fortune and success. Their operations fuelled the killings of people with albinism. Social Workers are the professionals responsible in assisting the Albinism disability psychosocial challenges due to their nature of job. In addition, they are in good position of linking social work helping theories with real or practical setting of albinism people societal life. Families are social units having or living with people with Albinism in the society.

Religious leaders are the spiritual leaders who are preaching the word of God. Also include physical, psychosocial and spiritual care. Apart from preaching they assist people with counseling, provide them with spiritual guidance and also in their congregations they encourage their people not to stigmatize people with Albinism but better to love them and assist them in any way they can.

3.6 Sampling Size

Sampling has been defined as the process of selecting the proportion of people drawn from large population, this therefore means that the sample stands as a representative of the population provided it has the same basic characteristics of the population from which it is drawn (Rwegoshora, 2006). About 52 respondents participated in the study for data collection for the purpose of the study. Respondents had the following characteristics 22 were People with Albinism, 14 were Families who had lived (or live) with Albinos / Religious Leaders, 4 were Traditional healers, 12 were Social Workers who work at Temeke Municipal Council.

Table 3.1: Sample Size and Distributions

S/N	Category of respondents	Frequency	Frequency (%)
1.	People with Albinism	22	42
2.	Families/ Religious leaders	14	27
3.	Traditional healers	4	8
4.	Social Workers	12	23
Total		**52**	**100%**

Source: Researchers Sample Distribution (2015)

3.7 Units of Inquiry

The study Units of Inquiry comprised women and men from the people with Albinism conditions and their leaders from TAS.

3.8 Sampling Methods

3.8.1 Purposive Sampling

The study used purposive technique under non-probability sampling to select particular units of the universe for constituting a sample that represents the universe. Purposive sampling, is also referred to as judgment, selective or subjective sampling characterized by an intentional effort to gain representative samples by including groups or typical areas in a sample (Kombo & Tromp, 2006). This reflects that the researcher relies on his/her own judgment and experiences to select sample group members.

Also the researcher opts for purposive sampling to select respondents according to their involvement, status and position in the Albinism issue. This was possible because researcher had adequate knowledge of research problem useful in choosing sample of experts and subjects that real involving in Albinism issue in Tanzania. Hence, researcher's skills and capabilities were key factors in selecting units who are typical representatives of the population of the study involved in Albinism psychosocial challenges and issues to participate and contribute to the accomplishment of research objectives and research outcomes. This sampling method was opted because:

It is less time consuming compared to other sampling methods because only appropriate participants will be involved. Outcomes of purposive sampling are usually more representative of target population compared to other non-probability sampling methods. Moreover, the sampling method is useful and appropriate way to recruit the members of rare or much sought after groups.

3.8.2 Simple Random Sampling (Probability Sampling)

Simple Random Sampling is another sampling technique used, whereby all population including members from TAS selected through purposive technique given an equal chance of being included in the sample, and the technique ensures each one to have same probability of being selected so as to reduce biasness in the sampling frame.

The researcher followed the following steps to create a simple random sample, including: **(**a) defining the population; (b) determining sample size; (c) listing the population; **(d)** assigning numbers to the units; (e) finding random numbers; and (f) selecting sample.

The advantage is that: through this process the simple random sampling reduces the potential for human biasness in the selection of cases that will be included in the sample of the study. Furthermore, the simple random sample gives us a sample that is highly representative of the population being studied, assuming that there is limited missing data. Finally, the method also allows us to make generalizations (i.e., statistical inferences) from the sample to the population have high external validity.

3.9 Data Collection Methods

The study used both Swahili and English languages to collect both primary and secondary data through Questionnaire and interviews to collect primary data from the respondents and documentary review for the secondary data. The study employed both qualitative and quantitative data. However, more qualitative approach has been employed because of its contextual nature and as it allows collection of data and other relevant information in the participants' settings (Creswell 2009). Important quantitative information like reports on Albinism situation obtained from government and other organizations. Different methods of data collection were used as follows:

3.9.1 Interviews

An interview is a set of questions administered through oral or verbal communication, or is a face to-face conversation (Kothari, 2008). In this study, open ended, unstructured and structured questions supplemented the areas where questionnaire were not suitable in data collection regarding to level of education. Interviews were conducted to collect data from the few people with Albinism who did not know how to read and write.

Researcher prepared and drafted an interview guide on a topic and plan for interviews schedule. During the interview, researcher recorded the conversations and transcribed them. The researcher opted the method as the method was very effective because it enabled the researcher to obtain more information on the how they feel regarding the psychosocial problems they face.

It also has exhaustive character if carefully and well used in research, as it can make deep exploration of respondents to obtain required data and information. It provides more valid information of respondents' attitudes, values and opinions as repondents contextualise the reserch problem. It also creates the atmosphere which encourages the respondents to be open and honest. Lastly, it enabled the researcher a room for flexibility in adjusting the questions and change the directions durig the interviews.

3.9.2 Questionnaire

Questionnaire is a set of questions that are usually sent to the selected respondents to answer at their own convenient time and return the filled in questionnaire to the researcher (Rwegoshora, 2006). In this study structured and standardized questionnaire with both open- and closed- ended questions administered to TAS members/Religious leaders, Social Workers and traditional healers. The method preferred as it is easy to cover a wide area compared to interview due to its merit and nature and minimized bias due to the phrasings responses. It also allowed the collection of large amounts of information from a large number of people in a short period of time and in a comparatively cost effective way. Questionnaire results are normally quickly and easily quantified by either a researcher or through the use of a software package such as SPSS.

3.9.3 Documentary Sources

The researcher used this method to collect secondary data. Various literatures relevant to the topic such as disability and albinism issues, previous studies, reports and books were consulted. This method helped the researcher to acquire information that was hardly found in other sources.

3.10 Methods of Data Processing, Analysis and Presentation

Qualitative and quantitative data processing methods were used in getting data ready for analysis. The collected data were coded by assigning numerals or other symbols to answers so that responses can be put into a limited number of categories to the research problem under consideration. The second stage was editing to detect errors and omissions so as to make sure that data are accurate and consistent with other facts gathered, uniformly entered as completed as possible.

Then data classified to reduce into homogeneous groups so as to get meaningful relationships and reduce the deviations. This involved arranging data in groups or classes on the basis of common characteristics. Finally, data were tabulated**.** Then Quantitative data were edited, coded and analyzed using the Statistical Package for Social Sciences (SPSS) for Windows computer software.

Moreover, the qualitative data collected from respondents were analyzed using the content analysis method. Qualitative responses description of attitudes, challenges, perceptions, beliefs, knowledge and coping strategies on albinism and people with difficulties of albinism were analyzed through content analysis by paraphrasing themes identified by respondents. Analyzed data presented using statistical summaries such as tables, bar charts, frequencies, and phrasing so as to make easy interpretations and information self-elaborative and easily understood.

3.11 Ethical Considerations

The study considered ethical issues by taking care of the quality of the collected data and to guarantee the privacy of the participants, personal data were kept anonymous for those who don't belong to the research group. Respondents were requested to participate free in the study.

One of the ethical issues considered when doing research is the seeking of permission for the study (Kerlinger, 1993). The Government circular letter Ref. No. MPEC/R/10/1 dated 4th July 1980 gives power to the vice Chancellor to issue research clearance to Students.

The researcher followed all logical and ethical consideration by seeking permission to conduct research in the Municipal. A Clearance letter from The Open University of Tanzania was presented to the Executive Director of Temeke Municipal Council who issued permission to collect data in the area. Furthermore, the researcher requested the respondents to fill the questionnaire assuring them of anonymity, privacy and that data collected to be used for this research only and were handled in strict confidence.

3.12 Limitation of the Study

The study would probably face some limitations that may affect direct conduction of the study. Timely availability of respondents might be one of the limitations whereby some of the respondents could be traced as agreed. The other key limitation also could be the state of willingness of the respondents to participate in the study. Not all respondents were positive to the study, some would pose some negations in order to be excluded in the study and some due to personal interest and ignorance, could reject to cooperate with the researcher.

Furthermore, the sample size and mode of inquiry, based on qualitative by nature, somehow limits the generalization of the study findings. In future, studies investigating Albinism genetic disorders could benefit from a broader PWA sample.

3.14 Data Validity and Reliability of Research Instrument

3.14.1 Validity of Data

The study conducted the internal validity test to the extent, which the data measures or reflects to what it was supposed to measure of the psychosocial challenges and coping strategies employed by PWA. For quality control, a pre-test, the instrument was given to individuals to give their opinion on the relevance of the questions using a 5-point scale of relevant, quite relevant, somewhat relevant, and not relevant. Moreover, the study checked for external validity to examine if the content validity measures the study objectives and how well the data collected can be generalized the population for which it was developed.

3.14.2 Reliability

Reliability is the consistency of a measuring device over time. Kothari (2009) define reliability as the degree to which an instrument measures the same way each time it is used under the same conditions with the same subjects. A test-retest method was applied by administering two times the questionnaire to the homogenous respondents, in one ward of Tandika in Temeke Municipal for comparing similarity and closeness.

CHAPTER FOUR

PRESENTATION AND DISCUSSION OF FINDINGS

4.1 Introduction

This chapter presents the qualitative and quantitative findings and discussions of results from the survey. These include respondents' demographics, research questions regarding the psychosocial challenges and coping strategies among persons with albinism in Tanzania. Some of the qualitative results are presented in the form of descriptions of themes collected through key informant interviews. The findings presentations are done in the form of tables explaining (frequencies /percentages) and bar/pie charts.

4.2 Respondents' Demographic Characteristics

Table 4.1: Respondents' Gender Pattern Frequency and Percentage

Respondents	Frequency	Percent	Valid Percent	Cumulative Percent
Male	28	53.8	53.8	53.8
Female	24	46.2	46.2	100.0
Total	**52**	**100.0**	**100.0**	

Source: Research Findings 2015

Respondents of different gender distribution participated in the study, about 28(53.8%) were males and 24(46.2%) were females. Therefore, the gender-based distribution of respondents was indicated. More males were involved by Tanzania Albinos Society compared to females where the research collected data from PLWA.

Table 4.2: Respondents' Age Distribution, Frequency and Percentage

Respondents of different ages	Frequency	Percent	Valid Percent	Cumulative Percent
12 - 25 years	8	3.8	3.8	3.8
26 - 35 years	13	28.8	28.8	32.7
36 - 45 years	15	32.7	32.7	65.4
46 years above	16	34.6	34.6	100.0
Total	52	100.0	100.0	

Source: Research Findings (2015)

From the findings; respondents of different ages were participated in the study. The findings indicated that minority of the respondents were youth 2(3.8%) aged between 12 - 25 years, 15(28.8%) respondents were between 26-35 years. Moreover, 17(32.7%) respondents were between 36- 45 years, and the largest age group of respondents was 18(34.6 %,) aged between 46 - 60 years. From the findings, it was indicated that the majority of the active respondents who participated in the study had reasonable age, indicating high experiences in Albinism and psychosocial challenges issues. Furthermore, meant that the Albinism and psychosocial challenges were cross cutting issues among the people with different ages in the country.

Table 4.3: Respondents' Education Level Distribution, Frequency and Percentage

Respondents' Level of education	Frequency	Percent	Valid Percent	Cumulative Percent
Basic education level	5	9.6	9.6	9.6
Secondary education level	17	32.7	32.7	42.3
Certificate/ diploma level	13	25.0	25.0	67.3
University education level	17	32.7	32.7	100.0
Total	**52**	**100.0**	**100.0**	

Source: Research Findings 2015

The study involved respondents with different level of education in data collection process. Most of them were Social Welfare Officers from Temeke Municipality, people with Albinism from different wards of Temeke Municipality such as Tandika, Mbagala, Kigamboni, Mbagala Kuu, Kijichi, Mtoni, Sandali, Azimio, Kisarawe II, Charambe, Kimbiji, Somangira, Yombo Vituka, Kilakala, Chamazi, Kiburugwa, Temeke, Kurasini, Kilungule, Keko, Mianzini, Kibondeaji, Kibada ,Chang'ombe, Toangoma, Mjimwema, Pembamnazi, Makangarawe, Vijibweni, Miburani and Buza.

The respondents' level of education was as follows the majority 17(32.7%) belongs to university level possessing various degrees in different disciplines; also respondents having Secondary education level were also 17(32.7%). Furthermore, 13(25.0%) respondents had a college level of education including certificate and diploma. The lowest category participated in the study were 5(9.6%) having the basic education. The findings imply that education pattern of respondents of the study indicates the significant level of education which was treasured in collecting valuable data responding to study objectives.

Table 4.4: Respondents' Occupation Pattern, Frequency and Percentage

Respondents		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	Businessmen	17	32.7	32.7	32.7
	Traditional healers	4	7.7	7.7	40.4
	Social workers	13	25.0	25.0	65.4
	others	18	34.6	34.6	100.0
	Total	**52**	**100.0**	**100.0**	

Source: Research Findings (2015)

The study involved people with different occupations and professions in order to gain their experiences in Albinism psychosocial challenges useful for the study. Respondents' characteristics in terms of occupation were most of the respondents came from other categories which contained different professionals occupied 18(34.6%) followed by businessmen 17(32.7%). The study also included 13(25.5%) Social workers who are key people in addressing psychosocial issues through their profession practices while the minority group participated was traditional healers who counted to 4(7.7%) only. This was important in collecting data that could contain different professional backgrounds, attitudes and experiences towards Albinism from community settings.

4.3 Person with Albinism

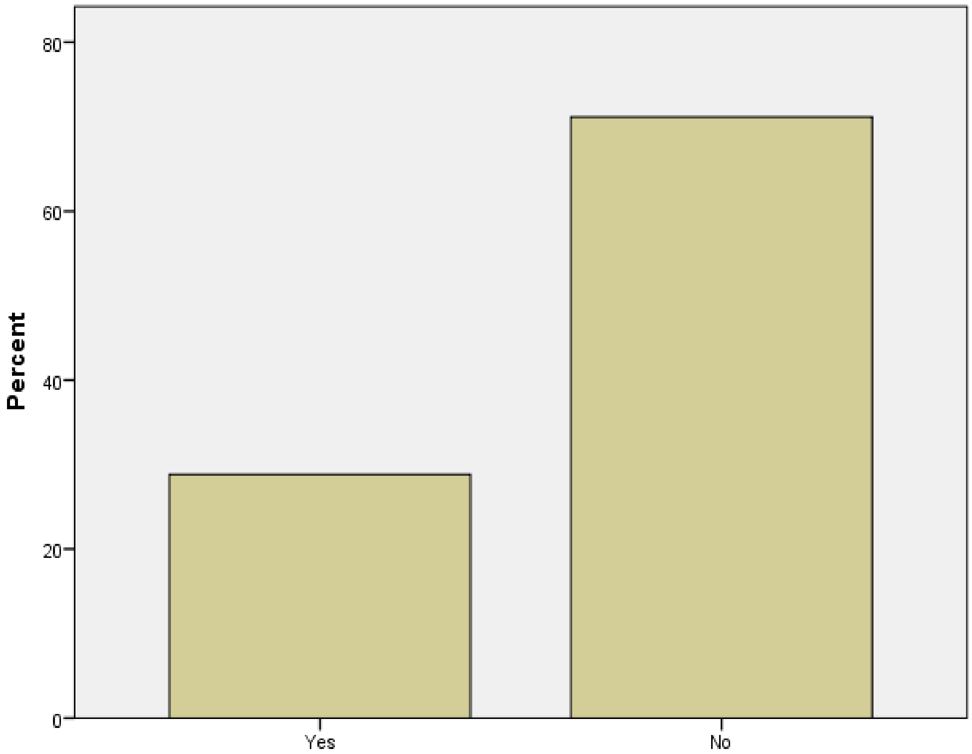

Figure 4.1: Person with Albinism

Source: Research Findings (2015)

Due to the nature of the study dealing with Albinism psychosocial issues, it assessed the distribution of people with Albinism who participated in the study. This targeted to get the inner feeling and coping strategies employed by them in responding to the society attitudes and perceptions. From the findings, only 15(28.1%) of respondents were people with Albinism while the rest 37(71.2%) were not belonging to albinism. This is important in getting various social and psychological reasons on the psychosocial challenges facing PWA.

4.3.1 Albinism within the Family

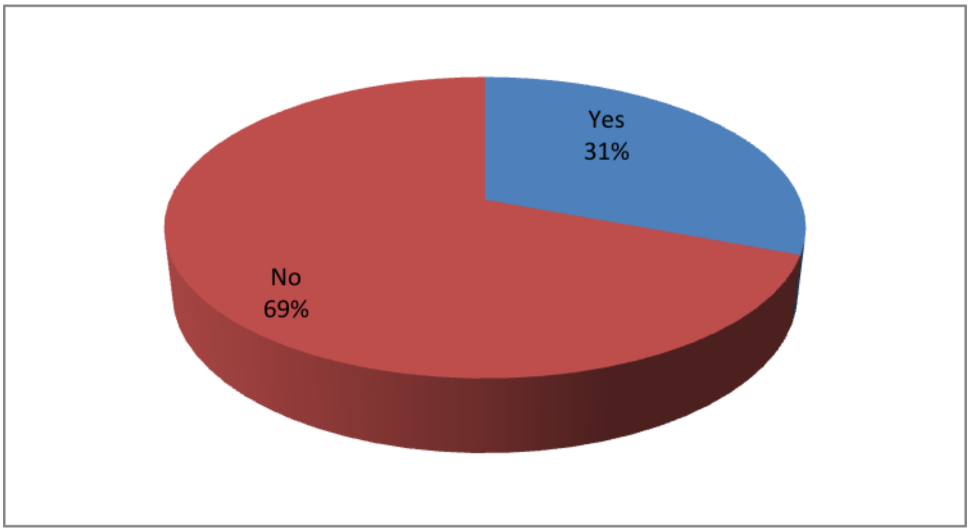

Figure 4.2: Albinism within the Family

Source: Research Findings (2015)

The respondents were asked to state if in their families they live and work with people with Albinism. The findings revealed that 16(30.8%) agreed that they have people with Albinism in their families/offices while 36(69.2%) of respondents did not live with people with Albinism. However, there was only addition of one respondent from non-Albinos participants as People With Albinism participated were

15. Therefore, from this percentage the study realized the responses that could be used to generalize the findings.

Before identifying the psychosocial challenges facing people with Albinism, it was important to identify their general and specific psychosocial needs regarding to their situation that can also be propelled to challenges they face.

4.3.2 PWA Specific Needs for their Psychosocial Wellbeing

Table 4.5: PWA Specific Needs for their Psychosocial Wellbeing

Specific needs for PWA	Frequency	Percent	Valid Percent	Cumulative Percent
Security and protection	14	26.9	26.9	26.9
Health education on how to prevent skin cancer	15	28.8	28.8	55.8
Protective clothing	7	13.5	13.5	69.2
Optician services	6	11.5	11.5	80.8
Mainstreamed in education and vocational training;	10	19.2	19.2	100.0
Total	**52**	**100.0**	**100.0**	

Source: Research Findings (2015)

The findings from both none and people with Albinism identified several need as follows: Health education on how to prevent skin cancer 15 (28.8), protective clothing 7(13.5%), security and protection 14(26.9%), mainstreaming in education and vocational training 10(19.2%) lastly, were Optician services 6(11.5%).

In addition, the literature identified more common psychosocial needs: needs for information, knowledge, skills to manage albinism, resulting illness, psychosocial counseling and emotional, economical support, logistical resources needs for social supports (Katon, 2003).

4.4 Societies Attitudes and Beliefs Towards PWA

The attitudes of the society have been complex towards People With Albinism. This study assessed those attitudes result in the table.

Table 4.6: People's Attitudes Towards PWA

		Frequency	**Percent**	**Valid Percent**	**Cumulative Percent**
Valid	Is resource for wealth	9	17.3	17.3	17.3
	Is misfortune in the family	11	21.2	21.2	38.5
	Disabled / abnormal people	15	28.8	28.8	67.3
	Normal human being	17	32.7	32.7	100.0
	Total	**52**	**100.0**	**100.0**	

Source: Research Findings (2015)

The results indicated that over 15(28.8%) of the respondents had negative attitudes towards albinism and PWA by viewing them as disabled/abnormal people, 11 (21.2%) view as misfortune in the family and 9(17.3%) view PWA as resource for wealth. But majority of respondents had positive attitudes toward PWA as 17(32.7%) viewed PWA as a normal human being like others in the society. The existing negative attitude shows that PWA are not safe in their psychological and social wellbeing as the community they live in, does not real support them like other communities across the world.

This was supported by the interviewed respondents who said:

> *"Due to negative attitudes, Children with albinism are hidden from the public, forbidden from socializing with others and treated as outcasts"*

This reflected that PWA suffer much from the rejection by the community and denial of their rights. These pose serious impact on their psychological and social status. In line with (Kiprono et al., 2012), asserts that due to negative attitudes towards albinism and PWA, many women have been divorced by their husbands and shunned by families after giving birth to children with albinism.

4.4.2 Perception on Treating Albinism as Disability or Non-disability

The study intended to know how people view albinism in respect of forms of disability.

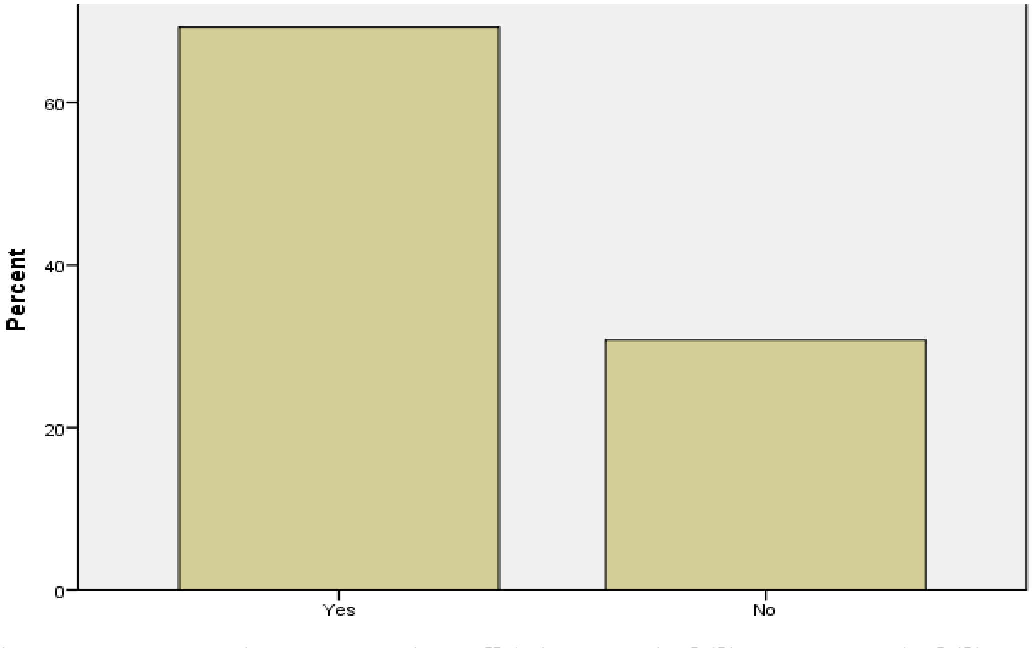

Figure 4.3: Perception on Treating Albinism as Disability or Non-Disability

Source: Research Findings (2015)

Moreover, there are contradictions between the professionals and common people on how to view the Albinism as form of disability or not. When study participants including people with Albinism asked, the response was as follows: 36 (69.2%) respondents agreed that albinism should be regarded as a form of disability while 16(30.8) disagreed by saying albinism is not a form of disability. Giving reason that albinism is just a deficiency of the melamine cells in their skin.

The findings indicated that still, there is poor understanding of albinism within the society linked to the reasons of continuing discrimination and social exclusion. However, literature argues that handicap are the obstacles a person encounters in the pursuit of goals in real life, no matter what their source which is the same happening to Albinism people ability (Rao et al., 2002).

4.4.3 Reasons for PWA being Disability

The study asked the respondents to identify the factors that propelled them to view Albinism as a form of disability. The following factors were mentioned:

Table 4.7: Reasons for PWA being Disability

Respondents views		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	Weakness in Melamine pigment	22	42.3	42.3	42.3
	Incapable eyes sighting	8	15.4	15.4	57.7
	White hair	5	9.6	9.6	67.3
	High risk to Cancer	5	9.6	9.6	76.9
	All above not applicable	12	23.1	23.1	100.0
	Total	**52**	**100.0**	**100.0**	

Source: Research Findings 2015

Thus Weakness in Melamine pigment was mentioned by 22(42.3%) respondents; incapable eyes sighting 8(15.4%) respondents while having white hair among albinos was mentioned by 5(9.6%) respondents. The exposure to high risk of Cancer due to lack of Melamine was stated by 5(9.6%). However, 12(23.1%) disagreed by mentioning all the above mentioned factors are not applicable. This implied that most of people in the society don't understand the real meaning of disability that needs intensive awareness raising in the Albinism situation.

4.5 Family Views on Albinism Effects in their Normal Family Daily Life

Table 4.8: Family Views on Albinism Effects in their Normal Family Daily Life

Family views		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	Stigma/stereotyped	16	30.8	30.8	30.8
	Isolation	17	32.7	32.7	63.5
	Discrimination	15	28.8	28.8	92.3
	No any effects	4	7.7	7.7	100.0
	Total	**52**	**100.0**	**100.0**	

Source: Research Findings (2015)

The effects to family resulted by being with people with Albinism in their families in relation society attitudes have varying according to education and traditions around the society. Thus, respondents identified several views from the society including being isolated by the society dominated the effects by having (30.8%) stigma and being stereotyped (30.0%), being discriminated by society (28.8%), moreover,only (7.7%) declared that they feel that there is no any effects from society.

The results reflected that still there is a negative attitude of the society towards PWA that needs the strategic and collective efforts to ensure that knowledge and education on Albinism is being widely spread and understood.

4.5.1 Views on Intellectual and other Capability of the People with Albinism

Apart from being viewed as disabled, the people with Albinism are also viewed as not common human beings by beliefs that they have abnormal capabilities in the intellectual and other issues. Respondents identified the following views:

Table 4.9: Views on Intellectual and other Capability of the People with Albinism

Respondents views on intellectual of PWA		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	The same as normal human being	26	50.0	50.0	50.0
	Exceptional compared to normal human being	9	17.3	17.3	67.3
	Poor in nature	14	26.9	26.9	94.2
	Have magnetism power in the body parts	3	5.8	5.8	100.0
	Total	**52**	**100.0**	**100.0**	

Source: Research Findings (2015)

About 26(50%) respondents viewed PWA are the same as normal human beings. They are exceptional compared to normal human beings, mentioned by 9(17.3%) respondents while being poor in nature viewed by 14(26.9%). Furthermore, believing that they have magnetic power in the parts of their bodies mentioned by 3(5.8%) respondents.

However, this large percent 36 (69.2%) in figure 2 above of the respondents viewed their ability as normal, being contradicted with high percent of people who agreed that Albinism is a form of disability meaning that disabled people are people with a certain form of handicap. Society attitudes also were examined on people reactions on Albinism baby born in the family results were as follows: According to respondents they were divided 59.0% of them viewed negatively saying families view the Albinism baby born in the family as disabled. The other 41.0% had positive reactions to albinism baby born.

One of interviewed respondents reacted that:

> *"Although the child is like other human being but I could be more happy to have children without Albinism"*

This was important as the literature indicated that, Children with albinism were instantly killed at birth for fear of shame attached to the condition or beliefs that they carry bad luck (CHRAGG, 2010). Due to such attitudes towards albinism, in Sukumaland, the murders went on unreported for long time and thus there is no reason to believe that it has ended (Jozen, 2012). It is then apparent that it is difficult to detach community committed to their traditional religions and cultures that existed before the coming of Christianity and Islam.

4.6 The Psychosocial Challenges Facing People with Albinism

The research question intended to identify the psychosocial challenges that have been facing the people with Albinism in their daily life. The study findings showed various psychosocial challenges ranging from structural to institutional settings in the country as stipulated in the Table 4.10.

Table 4.10: Psychosocial Challenges Facing PWA

Psychosocial challenges facing PWA		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	Prejudice/stereotyping	8	15.4	15.4	15.4
	Stigmatization and discrimination	13	25.0	25.0	40.4
	Dangerous life surroundings	10	19.2	19.2	59.6
	Marginalization	12	23.1	23.1	82.7
	Social services exclusion	4	7.7	7.7	90.4
	Excessive viscous circle of poverty	5	9.6	9.6	100.0
	Total	**52**	**100.0**	**100.0**	

Source: Research Findings (2015)

The findings from the study rated the challenges as follows: prejudice 8(15.4%), stigmatization and discrimination 13(25.0%), dangerous life surroundings 10(19.2%), marginalization 12(23.1%), social services exclusion 4(7.7%) and lastly, being faced by vicious circle of isolation and poverty 5(9.6%).

From the findings, indicated that people with albinism tended to be more withdrawn from social gatherings to avoid being noticed. This finding implied that due to this socially rooted discrimination, the quality of life of people with albinism are more likely to drop out of school and face more difficulties in employment and marriage compared to the rest of the population.

It was found in light of the traditional myths concerning albinism's etiology; are being subjected to a great deal of stigma and psychological distress. Results above also showed that, most of the people with Albinism are facing dangerous life due to unaccepted myths and maltreatment available in the society. Some people believe albinism is the result of a curse from the spirits of the family with a member of such a condition. And yet, in other places mixtures of Albino's body parts are thought to bring good luck and prosperity.

According to findings, many people with Albinism feel being stereotyped and it is dehumanizing to refer to a person in terms of a condition by calling unpleasant names. Teasing and name-calling are other ways of dehumanizing.

This was supported by interviewed respondents saying:

> *"Children encounter stereotyping during school years, and they need to develop positive coping strategies"*

The findings also indicated that in the early years and throughout life, family and close friends declare that stigma exists, has always existed, and will continue to exist. That is the appalling side of society where information is either lacking or absent about Albinism, that it's neither a curse, a plague, a disease. We do not deserve to be quarantined by our own society.

One among young PWA declared by saying that:

> *"Many people avoid mere physical contact with me. A shake hand greeting is something my schoolmates and even the community can't do except for a few who are informed, all because of my Albinism."*

Respondents 4(7.7%) identified, access to social services such as quality education has been difficult for some albinos due to structural and institutional settings. Health services had been difficult to most of Albino children who suffer from cancer, which is costly to treat. They are mostly abandoned and are taken care of in foster homes. Lastly, 5(9.6%) respondents identified that; persons with albinism are excessively affected by poverty. This can be linked with the structural discrimination and marginalization they face. From literature indicated inseparable linkage between discrimination and poverty creates vulnerability in the areas of economic and social rights.

4.6.1 Albinism Challenges in Social Interactions

The respondents were asked to identify family views on Albinism challenges in normal daily life whereby the respondents identified that having family member with Albinism has been accompanied by many challenges. The challenges to the family daily life identified in the Table 4.11.

Table 4.11: Albinism Challenges in Social Interactions

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	challenges on education attainment	10	19.2	19.2	28.8
	challenges on relationships	14	26.9	26.9	55.8
	challenges on employment	10	19.2	19.2	75.0
	challenges in health services	9	17.3	17.3	92.3
	Challenges for accountability for human rights violations committed.	2	3.8	3.8	96.2
	No any challenges	7	13.4	13.4	100.0
	Total	**52**	**100.0**	**100.0**	

Source: Research Findings (2015)

From the findings above indicated that: leading challenges mentioned was effect on relationships by 14(26.9%) respondents, this followed by challenges on education attainment mentioned by 10(19.2%) respondents also effects on employment mentioned by 10(19.2%) respondents.

Moreover, challenges for accountability in human rights violations committed by other people in the society identified by 2(3.8%) respondents and only 7(13.4%) said there was no any challenge in their family daily life for being with people with Albinism. The findings reflected that Albinism have impact in family members as they also experience discrimination from the community.

4.6.2 Names Given to Identify People with Albinism

Apart from the effects within the family daily living and social interactions challenges, respondents also mentioned some names that are used within society to identify them as shown in the Table 4.12.

Table 4.12: Names Given to Identify People with Albinism

Names given to PWA		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	*“Mzungu”* reflects to fake Whiteman	10	19.2	19.2	19.2
	“Zeruzeru” reflects to ghost/creature	25	48.1	48.1	67.3
	“Dili” reflecting to wealth due to superstitious beliefs	12	23.1	23.1	90.4
	Albino	5	9.6	9.6	100.0
	Total	**52**	**100.0**	**100.0**	

Source: Research Findings (2015)

One of the prominent names identified for them was *"Zeruzeru"* that relates them to ghosts/creatures identified by 25(48.1%) respondents, *"Dili"* refering to wealth due to superstitious beliefs mentioned by 12(23.1%) respondents. Others 10(19.2%) call them as *"Mzungu"* that reflects to fake Whiteman while 5(9.6%) of respondents mentioned Albino as nick names used to identify people with Albinism.

UTSS, (2012) support the findings by arguing that due to negative attitudes towards PWA, derogatory names for persons with albinism like Zeru Zeru, Albino, Mzungu, Dili, Dau, or Mkwanja (in Kiswahili) or Mbilimwilu (in Kisukuma) used. The presence of that humiliation names in the society indicate that society is still having unpleasant attitudes towards people with Albinism. Normally such names lead to prejudice and stereotypes, which lead societies to judge PWA basing on their condition and not appreciating their humanity.

4.6.3 Albinism Killings with Superstitious Beliefs

In the recent years, Tanzania has witnessed the mushroom of people with Albinism killings in the whole country specifically in northern parts related with superstitious beliefs. This had created the endangering life challenges for them; study examined the society views on the particular killings and the response stipulated in the Table 4.13.

Respondents agreed with the mushroom killings happening in Tanzania identified them as highly related with witchcrafts and superstitious among the people. The findings revealed that 20(38.5%) respondents identified prevalence of high ignorance has been contributing to the killings.

Table 4.13: Albinism Killings with Superstitious Beliefs

Respondents agreed due to the following reasons		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	PWA body parts help in political win	**14**	**26.9**	**26.9**	**26.9**
	Body parts brings wealth	18	34.6	34.6	61.5
	Ignorance of people (traditional healers)	20	38.5	38.5	100.0
	Total	**52**	**100.0**	**100.0**	

Source: Research Findings 2015

This was followed by wealth generation, which is also associated with the killings by 18(34.6%) believing that the Albino’s body can be used by traditional healers to bring wealth to a person. Other respondents 14(26.9%) agreed that the killings are highly associated with political ambitious that their body parts help in political win by mixing with other charms.

Braathen (2005) in a study in Malawi also revealed that in general the community lacks proper information and knowledge about albinism. Albinism was seen as a condition immersed in myths and superstition. Lund (2001) also identified that lack of knowledge about albinism leads to many superstitious beliefs when combined with poverty magnifies psychosocial problems on top of related problems to skin and eyesight.

This lack of correct knowledge on albinism, results in myths about albinos being spread which has horrifying effects on the albinos in Tanzania (Stensson, 2008). Nzagi (2009) insists that the lack of awareness of the condition is not only among those in rural areas, but also trained medical professionals. Furthermore, superstitions, myths and traditions were examined with beliefs of society towards it.

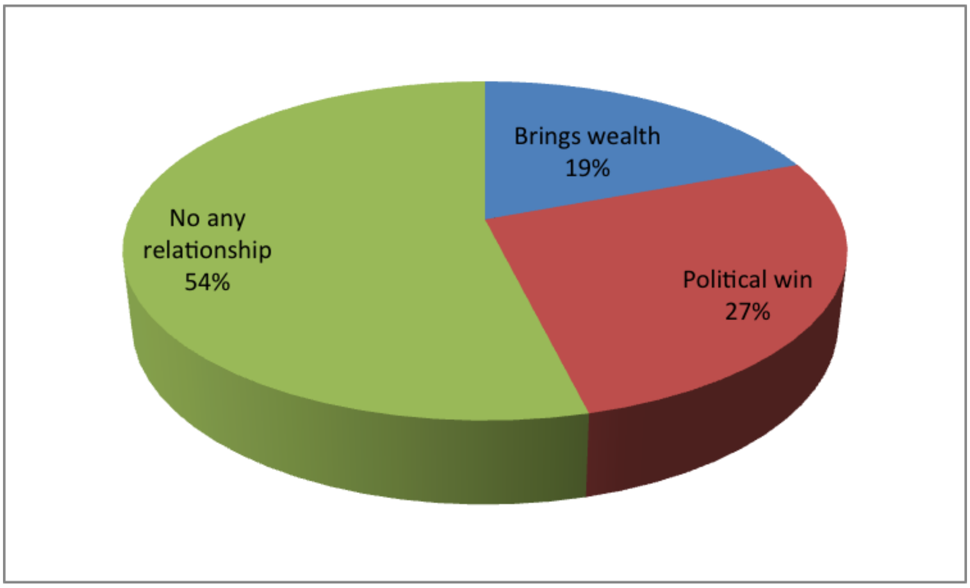

Figure 4.4: Beliefs on PWA Possess a Super Natural Power

Source: Research Findings (2015)

These run the spectrum from the notion that those with albinism have magical powers to the belief that they are lagging. Another common myth is that people with albinism bring wealth to the people, that was stated by 19% respondents while about 27% of respondents who said that PWA possess the natural power that associated with political win among the elections contesters. However, most of the respondents above 50% identified that there was no correlation between Albinism and PWA giving reason that:

> *"Albino is just a normal person as other human beings, it is not correct to relate them with wealth or political issues"*

The findings indicated that many people in the society agree that PWA have any magic or super natural power that can be linked with fortune. The findings and literature concluded that, quality of life of people with Albinism is severely affected and worsened by the lack of community awareness.

4.7 Psychosocial Coping Strategies being Employed by People with Albinism

Consequently with the psychosocial difficulties they are facing, PWA developed essential physical and emotional response to their individual experiences with albinism. These coping responses form adaptations strategies of being albinism. Respondents identified the coping strategies employed by people with Albinism as shown in the Table 4.14.

Table 4.14: PWA Psychosocial Challenges Coping Strategies

Psychosocial challenges coping strategies		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	Engagement coping strategies	5	9.6	9.6	9.6
	Disengagement coping strategies	14	26.9	26.9	36.5
	Avoidance coping strategies	11	21.2	21.2	57.7
	Family/self-help group formation	13	25.0	25.0	82.7
	Isolation coping strategies	9	17.3	17.3	100.0
	Total	**52**	**100.0**	**100.0**	

Source: Research Findings (2015)

Engagement coping strategies 5 (9.6%), disengagement coping strategies that a person with Albinism tried to escape from stressing stimuli by putting himself far from it 14(26.9%). Avoidance coping strategies found that people with albinism used it in regulating anger stimulation and was mentioned by 11(21.2%) respondents. About 13(25.0%) respondents mentioned family/self-help group formation this involved the family influence coping strategies: thus family members have accurate information about albinism.

Isolation coping strategies identified by 9(17.3%) is just the activities that will make distance between the people with Albinism with the entire society relationships. This implies that coping strategies is just the ‘first line of defense, but when intentional negative emotions are particularly intense and/or continued, avoidant individuals might be forced to rely on repressive coping to minimize distress.

4.7.1 Strength and Weaknesses of PWA Psychosocial Coping Strategies

The employed psychosocial emotional aspects of Albinism attitudes influence the personal experience through coping strategies although, it was believed to e very limited to actual relief of psychosocial relief. Therefore, the findings showed in the Table 4.15.

Table 4.15: Strength and Weaknesses of PWA Psychosocial Coping Strategies

Strength and weakness psychosocial coping strategies		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	Most of them are temporarily	10	19.2	19.2	19.2
	Not effective in addressing psychosocial effects	15	28.8	28.8	48.1
	Just increases psychosocial stress	10	19.2	19.2	67.3
	Very effective in addressing the psychosocial effects	10	19.2	19.2	86.5
	Not sure	7	13.5	13.5	100.0
	Total	**52**	**100.0**	**100.0**	

Source: Research Findings (2015)

The majority of respondents 15(28.5%) assert that most of strategies are not effective in addressing psychosocial effects. Just increases psychosocial stress as was mentioned by 10(19.2%). Having the value with respondents 10(19.2%), who said the coping strategies employed are very effective in addressing the psychosocial effects. On the other hand, respondents 9(17.3%) said most of coping strategies are temporarily based and lastly are respondents 7 (13.5%) claimed that they are not sure if the strategies are effective or not.

From the findings it revealed that most of the psychosocial challenges coping strategies among the people with Albinism do not effectively solve their problems. This implies the need of collective efforts among stakeholders in designing and implementing social, psychological and economical strategies in reducing the psychosocial difficulties as the society is the primary cause of those problems.

4.7.2 Respondents Comments on PWA Psychosocial Improvement

In line with the stakeholders, collective efforts in addressing the psychosocial effects caused by the challenges of the people with Albinism, the respondents suggested the following in the Table 4.16.

Results indicate serious punishment for criminals killing PWA by 17(32.7%) respondents insisted that laws should be provide quick and serious punishments. Enacting Laws and regulations protecting PWA have to be emphasized so as to address all forms of stigma and discriminations facing them. However, increase of awareness in education in the society was suggested by 11(21.2%) respondents. Researcher viewed that; education should start at elementary level to build awareness in eradicating unpleasant traditions and myths in the society.

Table 4.16: Respondents Comments on PWA Psychosocial Improvement

Respondents comments on PWA psychosocial improvement		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	increase education awareness in the society	11	21.2	21.2	21.2
	Encourage community self-help support groups	9	17.3	17.3	38.5
	Cooperation of Government and community in intervention	9	17.3	17.3	55.8
	Provision social services (heath protective equipment's)	6	11.5	11.5	67.3
	Imposing Serious punishment for criminals killing PWA	17	32.7	32.7	100.0
	Total	**52**	**100.0**	**100.0**	

Source: Research Findings (2015)

Moreover, encourage community self-help support groups identified by 9(17.3%) that will help in socioeconomic issues. Cooperation of Government and community in intervention by 9(17.3%) linked with collaborative efforts because the community is a primary source. Provision of quality social services such as health and education (heath protective equipment) is important as it will support PWA well-being, this was identified by 6(11.5%) respondents.

Literature also added that people with Albinism have to be supported in fostering friends and families that will listen to their experiences of frustration, anger, discouragement, or pride. Arguing that some ways it releases an emotional charge are physical activity, taking action in the form of education or advocacy, journal and letter writing, or doing something nurturing for them. The suggestions by respondents revealed the need of the strategic efforts in ensuring the psychosocial wellbeing, which has seriously affecting the well-being of the people with Albinism.

4.8 Discussions

Results show that while all respondents showed negative attitudes only, social workers had a slight higher proportion of respondents who had positive attitudes towards PWA. Traditional healers had negative attitudes and the same had positive attitudes. Such findings are of very painful experience for PWA who would need physical expressions of love, care, interactions and acceptance from the whole community. Lund et al. (2002) explain the negative attitudes towards PWA as unhappy consequence for PWA being labeled as socially unacceptable and that people's stigma can come to dominate the perceptions that others have.

In their life in Tanzania PWA have to cope with stigma and discrimination as in many African societies, they are viewed as misfortune. Many people in the society had very biased and stereotyped views of people with albinism as they described PWA as persons with white hair, white skin and red eyes. This has been a common myth generated within the community indicating that the truth about albinism is not widely known.

For example, there are numbers of myths and stories about albinism associating superstitions that a family with an Albino baby is a victim of witchcrafts. In continuation, some people believe that people with albinism do not die a natural death but simply go into the bush and disappear. Actually, these attitudes and beliefs need to be comprehensively addressed by raising community awareness on Albinism and PWA.

The negative attitudes have also been proven in whether to identify albinism as disability, as still people viewed it as disability. It also makes it difficult for those with albinism to identify themselves as a group. For many reasons, albinism can be seen as a very unique condition. Its uniqueness however, has led to separateness and isolation for many people. Social attitudes toward albinism are often similar to those experienced by other disability and minority groups.

These attitudes include a lack of understanding, fear of the unknown, and prejudice based on appearance. The findings also showed that their health and education concerns, people with albinism must also deal with psychological and social challenges. That contributed to more emotionally unstable and had less self-confident personalities than people without albinism. However, stress and social discriminations from the communities those still lack education about albinism's etiology prevailing within the community. Therefore, it is important for being valued as a whole person is the foundation for a lifetime of self-esteem and inner strengths.

According to Masakhwe, (2009) in his study on the challenges persons with albinism asserted that: face in having their cases brought to justice are grounded in the vulnerability of the population and include: the fear of further attacks, reprisals or further stigmatization; difficulties in finding witnesses owing to the ostracism they face within their community and, frequently, the involvement of family and community members in the attacks; the lack of awareness of legal rights; the lack of financial resources; the inadequate capacity of the judicial system to address such cases; the lack of legal aid and adequate legal representation; and the lack of knowledge or of confidence in the law enforcement and justice systems. From the findings, it revealed that most of the psychosocial challenges copping strategies among the people with Albinism were not effectively solving their problems. This implied that there was the need of collective efforts among stakeholders in designing and implementing social, psychological and economical strategies in reducing the psychosocial difficulties as the society is the primary cause of it.

CHAPTER FIVE

SUMMARY, CONCLUSIONS AND RECOMMENDATIONS

5.1 Introduction

This chapter provides the summary of the research findings, conclusions and the recommendations from the study. The discussions, conclusions and recommendations were made in accordance with the research objectives on psychosocial challenges faced by persons with Albinism and their coping strategies.

5.2 Summary

The study intended to investigate the psychosocial challenges facing people with Albinism and what have been used by those people as coping strategies towards effects brought to them. Almost two over third of respondents in this study, agreed that there was high stigmatization and discrimination facing the PWA in their areas. This finding indicated that stigma and discrimination have a sinister impact on the self-image and self-respect to PWA. This has been affecting the psychosocial well-being of people with albinism in Tanzania.

The study also found that societal attitudes towards albinism and PWA is negative, largely associated with a high level of illiteracy and ignorance in the community they live. Findings identified that the killings of the PWA and the fear of harm have adverse effects on social interactions which seem to deprive their interacting ability contributing to be emotionally unstable with less self-confident traits.

The study also indicated that the increasing killings of PWA in Tanzania is highly based on the myths and beliefs that body parts of albinos are the devices in gaining material wealth or winning political posts. This belief has increased anxiety to many of them hence, live with high fear leading to trauma and depressions.

Though the government of Tanzania publicly condemned such killings and pledged to prosecute all the individuals or groups who were involved in such ritual killings and provide adequate protection to the PWA, killings still continue after governmental intervention. The study results showed that increased community awareness and setting could be a proper solution in reducing stigma and discrimination.

However, it was found that it has been difficult for the PWA to afford health facilities needed by them in protecting their health such as protective equipment of direct sun rays periods that predisposing albinos to skin cancer. Direct bright sunlight also worsens their already poor eyesight making it difficult for them to undertake activities such as tailoring, which requires good eyesight. Education attainment has been difficult to them basing on the stigmatization, stereotyping and discrimination children face in school settings.

Furthermore, some parents do not send children with Albinism to school believing that nothing can done by such children. The findings propelled the need of comprehensive Public health programmes to take into account the various challenges facing people with albinism in addressing the medical concerns of this population. A good example is the Regional Dermatological Training Center (RDTC) in Moshi, Tanzania which runs a mobile skin care clinic where a doctor and a nurse regularly visit villages to check the skin of the people with albinism and provide education on protection from UV exposure. The study also noted that quality of life of the PWA is severely affected and worsened by the lack of community awareness, cultural beliefs and superstitions within the society. Poor performance in the formal education and a discriminating work environment result to this economically disadvantaged group of individuals that is overwhelmed in a viscous circle of isolation and poverty.

Also the government and communities have not done much to identify weak areas in this circle in order to improve the quality of life of their citizens particularly those with albinism. The study also revealed various coping strategies employed by PWA in addressing the psychosocial challenges as follows: Engagement coping strategies, Disengagement coping strategies and avoidance strategies.

Avoidance coping strategies is just escaping the threats or related emotions. Family/self-help, group formation this involves the family influence coping strategies. In isolation coping strategies, PWA strives to keep away from unpleasant stimuli or situation from the external environments. Disengagement coping strategies is emotionally based on attempts to escape the feelings of distress done by PWA.

In addition, Engagement coping strategies is just the release of psychosocial tensions by seeking support, emotion regulation and acceptance. However, respondents largely rejected that identified coping strategies employed are not the permanent solutions to negative attitudes and other forms of marginalization such as stigmatization, stereotyping, discrimination and poverty they face. About 50% of respondents viewed the strategies as temporarily basis and they are not real addressing the psychosocial problems.

5.3 Conclusion

From the study conducted, it can be concluded that PWA still face many psychosocial challenges in their daily life. These challenges are highly resulting from environmental and social factors, which include negative attitudes and perception towards Albinism. From these circumstances, most of them use various coping mechanisms that they believe can help them in adapting with severe trauma and depression from stigmatization, isolation and prejudices from the society.

However, the employed engagement, disengagement, avoidance and isolation coping strategies have been effective in helping them to suppressing emotions, stress, depression and physical difficulties they face and enhance their psychosocial wellbeing. Also the presence of wrong society's attitudes about albinism is highly affecting their normal living, growing, and intellectual development. Consequently this external influence of society has been vital and essential emotional response of individual experiences with albinism. These cropping personal responses are forms of adaptations strategies of albinos. The family and community member have a significant contribution on psychosocial challenges facing persons with albinism.

The psychosocial challenges and coping strategies could be effectively if the government and society could ensure Albinism awareness, law enforcement and justice systems; increased financial resources; the increased capacity of the judicial system in combating such cases; increased legal aid and adequate legal representation. Also professional service help from a therapist or counselor is needed to assist a person in highly charged issues of albinism as it is not easy coping with albinism.

5.4 Recommendations

Based on the study findings and conclusion, the study recommends the following:

(i) Therefore, the study recommends the need of strategic efforts in education provision so as to raise awareness on Albinism in the whole society. Due to ignorance, association between education and favorable attitudes towards albinism shows that, education can help in changing people's negative attitudes towards albinism. Moreover, education would discourage superstitious practices that affect the rights of people with albinism.

(ii) States should develop appropriate strategies in order to assist people with albinism in social, psychological and economic challenges in their daily life that include the following:
   (a) Integrate albinism awareness in the school curricula, especially to correct misconceptions about the etiology of albinism.
   (b) Provide more psychosocial counseling services in the country.
   (c) Train health care providers and community about albinism and the effects that UV exposure on the skin and eyes.

(iii) Prepare the good environment that can encourage community self-help support groups that can create employment for assisting PWA in their respective community settings.

(iv) States should have guarding and protecting measures against attacks to persons with albinism, tallying with international commitments on human rights, which are treasured in local laws as well as international human rights legal instruments.

(v) Religious authorities should cooperate to protect people with albinism and discourage any attack against them. Religious leaders have the role to provide their followers with guidance, which would address the problems facing people with albinism.

(vi) Community should abolish cultural beliefs that contribute to the killings of people with albinism due to obsolete myths and superstitions, instead; should encourage increase in socialization that will create positive attitudes towards PWA.

(vii) It is essential that the departments directly dealing with PWA specifically health and education, should enact or orient and implement policies pertaining to albinism disorders.

(viii) However, formulation of those policies should be participatory by involving people with albinism and their families in their development and implementation. This, in turn, will enhance their self-esteem and promote a sense of belonging as well as self-development and growth.

5.4 Further Research

(i) Further research on ‘self-concept’ is essential so as to determine the ‘inner or real self’ of people with albinism to the effect of the environment in enhancing their self-concept.

(ii) Conduct extensive research/surveys to determine on how do the PWA cope with psychosocial challenges in rural areas and the failure of employed coping strategies impacts in their well-being. Based on research information, develop appropriate strategies for assisting people with albinism.

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APPENDICES

Appendix 1: Questionnaires for People with Albinism/Family Member/Religious Leaders

People with Albinism/ family member/ religious leaders

Dear respondents,

Provided below is a set of questions that requires your attention and response. The questions are designed to meet the academic objectives. The main purpose of this questionnaire is to get information that will assist me in my research on the Psychosocial Challenges and coping strategies among persons with albinism in the country.

The Study is also conducted as partial fulfillment for award of Masters of Social Work of The Open University of Tanzania.

Thank you.

Nzelwa Sarah, R.

1. Person with albinism/family member? ________________________________
2. Gender___________ Age_______________ Region________________

   occupation________________________ Level of education________________
3. Are there relatives who have albinism? Yes ( ) No ( )
4. Is it right to consider people with albinism as disabled/handicapped? Yes ( ) No ( )

Explain your response ……………………………………………………………

(a) Weakness in Melamine pigment ( )

(b) Incapable eyes sighting ( )

(c) White hair and high risk to Cancer ( )

(d) All above not applicable ( )

5. What are specific needs of PWA psychosocial needs?

6. How does albinism affect their daily lives and that of immediate family? Probe for narratives of stigma, isolation, discrimination

   (i) Stigma/stereotyped ( )

   (ii) Isolation ( )

   (iii) Discrimination ( )

   (iv) No any effects ( )

7. How does albinism affect the daily your life and that of your immediate families?

8. What are psychosocial needs of people with Albinism?

   (i) Security and protection ( )

   (ii) Health and education on how to prevent skin cancer ( )

   (iii) Protective clothing and Optician services ( )

   (iv) Mainstreamed in education and vocational training ( )

9. What are psychosocial challenges do you face in your daily life (prejudice, marginalization, stigma, and discrimination)
   (i) Prejudice/stereotyping ( )
   (ii) Stigmatization and discrimination ( )
   (iii) Dangerous life surroundings ( )
   (iv) Marginalization Social services exclusion ( )
   (v) Excessive viscous circle of poverty ( )

10. How would you relate albino killings to witchcraft beliefs and superstitions?
   (i) PWA body parts help in political win ( )
   (ii) Body parts bring wealth ( )
   (iii) Ignorance of people (traditional healers) ( )

11. How would you relate beliefs about albinos to economic gains in their families and the entire community?
   (i) Brings wealth to the people ( )
   (ii) Political win among the elections contesters ( )
   (iii) There no correlation between Albinism all above ( )

12. Briefly describe the attitudes of community members towards you as person with albinism
   (i) Is resource for wealth ( )
   (ii) Is misfortune in the family ( )
   (iii) Disabled / abnormal person ( )

(iv) Normal human being ( )

13. What are descriptions, labels and names people often use to refer to PWA in this community?
    (i) *Mzungu”* reflects to fake Whiteman
    (ii) *Zeruzeru”* reflects to ghost/creature
    (iii) *Dili”* reflecting to wealth due to superstitious beliefs
    (iv) Albino

14. How does living with albinism affect social interactions in this community?
    (i) Effect on education attainment ( )
    (ii) Effect on relationships ( )
    (iii) Effect on employment ( )
    (iv) Effects in health services ( )
    (v) Effects on accountability for human rights violations committed ( )
    (vi) No any effect ( )

15. Tell me about your daily life experiences owing to superstations and beliefs about the albinism trait in your family? ……………………………………….…

16. What are the powers do people say that albinos have? ……………………..
    Is this true in your view? Yes ( ) No ( )

17. What are coping strategies used by Albinos in addressing the psychosocial challenges they face?

(i) Engagement coping strategies ( )

(ii) Disengagement coping strategies ( )

(iii) Avoidance coping strategies ( )

(iv) Family/self-help group formation ( )

(v) Isolation coping strategies ( )

18. What are the strengths and weaknesses of the used coping strategies?

(i) Most of them are temporarily ( )

(ii) Not effective in addressing psychosocial effects ( )

(iii) Just increases psychosocial stress ( )

(iv) Very effective in addressing the psychosocial effects ( )

(v) Not sure ( )

19. What can you comment about the society's views on Albinism in the area you are living?

(i) Increase education awareness in the society ( )

(ii) Encourage community self-help support groups ( )

(iii) Cooperation of Government and community in intervention ( )

(iv) Provision of social services (heath protective equipments) ( )

(v) Imposing Serious punishment for criminals killing PWA ( )

THANK YOU FOR YOUR PARTICIPATION

Appendix 2: Questionnaire for Social Workers

Dear respondents,

Provided below is a set of questions that requires your attention and response. The questions are designed to meet the academic objectives. The main purpose of this questionnaire is to get information that will assist me in my research on the Psychosocial Challenges and coping strategies among persons with Albinism in the country.

The Study is also conducted as partial fulfillment for award of Masters of Social Work of The Open University of Tanzania.

Thank you.

Nzelwa Sarah, R

1. Gender……… Age………. Region…………….. Occupation………… Level of education……………..
2. What myths, superstitions about albinos in the past and at present in this community…………………………………
3. What are the popular names given to people with albinism (explain the meanings and reasons linked to each label ……………………………………..
4. 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? ………………………
5. Would you say that albinos are treated in the same way as disabled people, such as the lame and blind? Explain……………………………………

6. What do you think about the intellectual and other capabilities of people with albinism? …………………………………………………………………..

....

7. What are psychosocial challenges do they face in their daily life (prejudice, marginalization, stigma, and discrimination) ……………….........................

....

8. How does albinism affect daily life of albinos and their immediate families? Probe for narratives of stigma, isolation, discrimination and marginalization,

……………………………………………………………………………..

....

9. How would you relate albino killings to witchcraft beliefs and superstitions?

……………………………………………………………………………..

....

10. Briefly describe the attitudes of community members towards people with albinism

……………………………………………………………………………

....

11. How does living with albinism affect social interactions in this community?

……………………………………………………………………………

....

12. What powers do people say that albinos have? Is this true in your view?
    ………………………………………………………………………………………
    ....

13. How do you think the life of albinos in Tanzania and East Africa in general can be improved? What should the government, NGOs and general public do?
    ....

14. What do you think are coping strategies used by Albinos in addressing the psychosocial challenges they face?...
    ………………………………………………………………………………………

15. In view of 14 above, what are the strengths and weaknesses of the coping strategies used by Albinos? …………………………………………………….
    ....

16. What can say about society perception towards people with albinism?.............
    ....

17. How cultural attitudes and misconception about albinos can be changed for improvement of their self-esteem and dignity? ………………………………..
    ....

18. What can be done to improve the psychosocial life of persons with albinism?
    ....
    ....

THANK YOU FOR YOUR PARTICIPATION

Appendix 3: Questionnaire for Traditional Healers

Dear respondents

Provided below is a set of questions that requires your attention and response. The questions are designed to meet the academic objectives. The main purpose of this questionnaire is to get information that will assist me in my research on the Psychosocial Challenges and coping strategies among persons with Albinism in Tanzania.

The Study is also conducted as partial fulfillment for award of Masters of Social Work of The Open University of Tanzania.

Thank you.

Nzelwa Sarah, R

1 Gender___________ Age_______________ Region________________
Specialization___________________ Time spent in career_______________

2 Tell me about past and current beliefs about albinos in this community? Are there any differences in beliefs in the past and contemporary societies?
…………………………………………………………………………………

3 Which special powers do witchdoctors and other healers associated with PWA have over time?
…………………………………………………………………………………

4 What do you know about what people say about albino body parts and medical or magical portions?
....

5 Do people in this community yet believe that albinos have supernatural powers? Do you know any case?
....

6 Did healers in the past use parts from albino bodies for medical and magical reasons? ....
Explain what do you consider to be the extreme myths about albinos?
....

7 Why are albinos believed to be associated with mystical forces/powers?
....
....

8 Do you think some healers yet seek albinos for medical and magical activities? Please explain your response?
....
....

9 What attributed to the powers that are believed to be inherent in albinism?
....
....

10 Do you think albinos faces any psychosocial challenges in their daily life?
……………………………………………………………………………..…
……………………………………………………………………………..……

11 What initiatives or strategies do Albino employ in coping with this psychosocial challenges in their daily life……………………………………
……………………………………………………………………………..…
……………………………………………………………………………..……

12 How do you view/perceive people with albinism in Tanzania?
……………………………………………………………………………..…
……………………………………………………………………………..……

THANK YOU FOR YOUR PARTICIPATION