An Investigation into the Psychosocial Implications of Oculocutaneous Albinism. A Case Study of Manicaland Albino Association.

Submitted

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Abstract

The study sought to investigate the psychosocial implications of oculocutaneous albinism (OCA) among members of the Manicaland Albino Association in Mutare urban. The study was anchored on four objectives that were: to establish the psychosocial challenges that members of the Manicaland Albino Association are facing in Mutare urban, to establish the attitudes and beliefs associated with oculocutaneous albinism among members of the Manicaland Albino Association in Mutare urban, to explore the extent of stigma and discrimination among members of the Manicaland Albino Association in Mutare urban and finally to establish the coping strategies being employed by members of the Manicaland Albino Association in Mutare urban. In order to comprehend oculocutaneous albinism as a disability and its psychosocial implications the study utilized the social model of disability as its theoretical foundation. Data was gathered using the simple random sampling technique to target 30 respondents with OCA.The study purposively identified 3 key informants which included the chairperson of the Manicaland Albino Association, the coordinator of the National Association of Non-governmental Organizations Mutare and the Department of Social Services head Mutare. Additional data also came from the purposively selected 2 focus group discussions, one with persons with albinism and the other with care facilitators. Employing the Rosenberg self esteem scale, 30 respondents were interviewed to measure their self esteem scores. The study established that psychosocial challenges faced by persons with OCA include stigma and discrimination and they have influenced the society behaviour and attitudes towards them. Some of the psychosocial challenges confronting persons with OCA manifested themselves in the marriage institution whereby they were finding it complicated to establish steady marriage partnerships owing to the myths and misconceptions aggravated by a society that is yet to entirely comprehend the condition. The condition for women with OCA was further compounded by gender dynamics. Findings on the marital status, level of self esteem, educational level and types of employment points to the fact that institutional discrimination as conceived by the social model of disability is negatively affecting the quality of life of persons with OCA. The study established that stigma and discrimination provoked emotions like anger and crying and in some cases it leads to depression. The study established that in face of these challenges persons with OCA engage coping strategies that range from emotional release and social support from the church, individuals and other non religious organisations. The research established that the family plays a critical role in accommodating persons with OCA. From the study 100% of the respondents felt that the family understands and appreciate the condition. The study concluded that persons with OCA do face psychosocial challenges hence it came up with recommendations that will challenge the stigma and discriminations faced by persons with OCA.This include an aggressive awareness campaign on the rights of persons with OCA and the amendment of the Disabled Persons Act (chapter 17.01) that will enable persons with OCA to have a legal backing in an effort to address issues of social exclusion.

Acknowledgements

Dedication

This thesis is dedicated to my parents Jesca and the late Newton whose words of support and push for persistence ring in my ears. You instilled the spirit of determination in me. My wife Sarudzai and daughter Zoe you, were there for me. I also dedicate this dissertation to all cadres championing the rights of persons with albinism.

Thank you, Lord for all the blessings.

To God be the Glory.

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List of acronyms

AIDS	Acquired Immunodeficiency Syndrome
BEAM	Basic Education Assistance Module
FGD	Focus Group Discussion
HIV	Human Immunodeficiency Virus
KII	Key Informant Interview
MAA	Manicaland Albino Association
NGO	Non-governmental Organisation
NOAH	National Organization for Albinism and Hypopigmentation
OA	Ocular Albinism
OCA	Oculocutaneous Albinism
UPIAS	Union of the Physically Impaired Against Segregation
ZIMAS	Zimbabwe Albino Association

CHAPTER 1

1.0. INTRODUCTION AND BACKGROUND TO THE STUDY

1.1 Introduction

This chapter will elaborate on the background to the study. The background study is to discuss briefly on the etiology of oculocutaneous albinism and why it may be considered as a disability hence this calls for the study to define the term disability premising it on the social model of the disability perspective. The chapter is going also to highlight some of the psychosocial challenges faced by persons with oculocutaneous albinism. This will be followed by an outline of the statement of the problem, justification of the study, aim of the study, its objectives, research questions and finally the organisation of the study.

1.2 Background to the Study

According to Kagore and Lund (2005) albinism is classified into two major categories 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 consequence in the pigmentation of the skin and hair (Oetting, Brillian and King, 1996). The study is to investigate the psychosocial implications of OCA and the coping strategies employed by members of the Manicaland Albino Association in Mutare Urban.

Gronskov, Ek and Nielsen (2007) estimated that global prevalence rate of albinism is 1 in 17000. In Zimbabwe and other developing countries the prevalence rate of albinism vary partly due to

the lack of the political will by the government to conduct a thorough baseline and collation of data. Professor Makumbe being quoted by the Newsday newspaper indicated that there are approximately 15000 persons with albinism in Zimbabwe (www.newsday.com) whilst on the other hand Lund (1996) established that the prevalence rate of OCA in Zimbabwe is 1 in 4728. In Zimbabwe these figures may represents a group that is socially excluded and oppressed due to stigma and discrimination.

According to Lund (1996) it is debatable to classify OCA as a disability. In Zimbabwe this debate has manifested itself in the country constitution and various pieces of legislation like the Disability Act of 1992. These pieces of legislation by implication classify persons with OCA as disabled, aggravating the ambiguity around the condition which ultimately affects the psychosocial life of persons with this condition (www.newsday.co.zw). The physiology of persons with OCA has resulted in impaired vision, myths and misconceptions due to lack of knowledge on the etiology of the condition.

Visual impairment is as a result of nystagmus, strabismus, photophobia and astigmatism (Oetting et al, 1996). Persons with OCA experience nystagmus which is characterized by the involuntary movement of the eyes usually sideways and sometimes up and down (www.childrenseyesinlondon.com). Oetting et al (1996) indicated that persons with OCA also experience strabismus, which is a result of muscle unevenness within the eyes causing the person to have a squint and tend to use each eye independently hence they do not have a binocular vision. Persons with OCA also suffer from photophobia which is defined as a sensitivity or intolerance to light and can cause great discomfort to those affected by it (Oetting et al, 1996).

They also suffer from astigmatism because the surface of the eye is not globular hence a distortion in the images seen by persons with OCA (Oetting et al, 1996).

As highlighted above the physical appearance of persons with OCA has triggered blatant stigma and discrimination (Kagore and Lund, 2005). Mtetwa (2012) asserted that persons with disabilities have progressive goals just as any other individuals in the society and should enjoy the provisions of international law and local constitution and pieces of legislation and policies that cherish the inherent worth and dignity of a person. Nevertheless it is not the case with persons with OCA as they face numerous psychosocial challenges that are embedded in the various socio-economic and political structures of the society (Charlton, 1998). Access to social services like education and health has been curtailed among persons with OCA because of stigma and discrimination. The situation is worse in Africa, where persons with OCA stand in stark contrast to the black pigmented population (www.ncbi.nlm.nih.gov). In this regard one can see that stigma and discrimination occurs at institutional and structural levels.

The various socio-economic and political structures in the society constitute the institutional and structural discrimination that imposes barriers on persons with OCA hence affecting their psychosocial life (Kagore and Lund 2005). Institutional and structural discrimination are located in government law and policies, the private sector and the social institutions like religion and marriage (Pincus, 1994).

Mtetwa (2012) pointed out that the Disabled Persons Act of 1992 is evidence on how persons with disabilities are institutionally and structurally discriminated. Mtetwa (2012:180) citing the

Disabled Persons Act stated that, *"an employer shall not be deemed to have discriminated against a person with disability if:*

(b) the disability in question was a relevant consideration in relation to the particular requirements of the employment concerned; or

(c) special facilities or modifications, whether physical or administrative or otherwise are required at the work place to accommodate the disabled person which the employer cannot reasonably be expected to provide".

Mtetwa (2011) further argued that the Disabled Persons Act is an antithesis of the social model because its places more emphasis on its provisions based on the medical model of disability hence society perceives persons with disabilities as charity cases.

Kagore and Lund (2005) pointed out that OCA is associated with various myths and misconceptions that trigger cases of teasing and name calling which affects levels of self esteem among persons with OCA.

Goffman (1963) pointed out that stigma refers to a mark which entails moral inferiority on the beholder. Although the practice of physical marking is no longer rampant, a powerful substitute has emerged in the form of social markings which has resulted in persons with OCA being excluded socially (Goffman, 1963).These social markings have been cemented by use of demeaning and derogatory language in reference to persons with OCA. This was further pointed out by Okoro (1975) when he said that language is used to subjugate persons with OCA to stigma and discrimination and is also used to convey these social markings. In the local Shona

language there are demeaning and derogatory words that are used to refer to persons with OCA. These include the word *'sope'* and *'jechwe'* denoting something that is supernatural and occupied by bad spirits (www.africasia.com).

Stigma and discrimination has also been manifested in the marriage institution. For example women with oculocutaneous albinism find it difficult to establish marriage relationships because men avoid them for fear of bearing a child with albinism. Lund (1996) asserted that such appalling levels of ignorance exhibited in the form of misinformation, stereotypes, prejudice and superstition evident in various societies has negatively affected the psychosocial well being of persons with OCA. Despite the glaring need for aggressive awareness campaigns on the rights of persons with OCA, many governments and their partners are found wanting (www.africasia.com).

The stigma attached to oculocutaneous albinism brings about suffering and embarrassment to persons with the condition and their parents (Lund, 1996). According to Miller and Major (2000) stigma and discrimination are sources of depression, guilt and anger among persons with OCA. Lund (1996) went on to note that due to the negative societal attitudes towards persons with OCA they have high chances of dropping from school and this compound the opportunities for them to be gainfully employed in future.

NOAH (2005) stated that negative cultural beliefs have a negative bearing on the rights of persons with OCA.They include the belief that body parts can be used in witchcraft to bring wealth and prosperity hence triggering the murder and mutilation of persons with the condition.

It is out of such callous events that the human rights approach to foster social change born out of the social model of disability have been enshrined by various governments to challenge the social oppression of persons with OCA (NOAH, 2005).

In some societies OCA is perceived as retribution from the spiritual world and this triggers socially entrenched stigma and discrimination that has a negative bearing on the quality of life of persons with OCA (www.ncbi.nlm.nih.gov).

Reeve (2004) cited in Mtetwa (2012) asserted that due to the concerted exposure to stigma and discrimination persons with disabilities can internalize oppression and this results in low levels of self esteem. Nevertheless some persons with disabilities have challenged the institutional and structural discrimination faced and have high levels of self esteem (Lund 1998).

In line with the foregoing discussion this study treats OCA as a disability. Disability is defined by the social model of disability as; *"the disadvantage or restriction of activity caused by a contemporary social organisation which takes little or no account of people who have impairments and thus excludes them from the mainstream of social activities"*(UPIAS (1976:14). In the same vein, Charlton (1998) further elaborated that the fundamental tenet of the social model is that disabled persons are subject to oppression and negative social attitudes, which inexorably emasculate their personhood and their status as full citizens.

This study is to investigate the psychosocial challenges faced by persons with OCA, their coping strategies and finally the paper is to come out with recommendations to improve the quality of life for persons with OCA.

1.3 Statement of the Problem

Persons with oculocutaneous albinism are human beings that should enjoy their lives just like any other person, however in Zimbabwe and other countries this is not the case as some of them are facing various psychosocial challenges that include stigma and discrimination resulting in social exclusion and low self esteem. Social exclusion has also resulted in persons with OCA needs not featuring on the national agenda hence negatively affecting their access to medical needs. According to Land and Kagore (2005) stigmatization and discrimination among persons with OCA has also resulted in emotions that include anger, depression and a guilty conscience.

Faced with these challenges, persons with OCA utilize various coping strategies that range from seeking social support and releasing emotional tension through crying. Okoro (1975) pointed out that persons with oculocutaneous albinism may tend to avoid social situations as a negative coping strategy of stigma and discrimination. It is against this background that the study seeks to investigate the psychosocial implications of OCA and explore the coping mechanisms employed.

1.4 Justification of the Study

The study is critical as a basis for policy formulation in order to improve the quality of life of persons with oculocutaneous albinism. The findings from the study will be useful for advocacy work around OCA in an endeavor to improve persons with OCA psychosocial life. It is hoped

that the explored coping strategies for persons with OCA are to be adopted by various helping organisations thereby strengthening programming. To add on to that, the study will contribute to the body of knowledge on the psychosocial implications of OCA.

1.5 Aim of the Study

The aim of the study is to investigate the psychosocial implications and explore the coping strategies of persons with oculocutaneous albinism in Mutare urban among Manicaland Albino Association members.

1.6 Objectives of the Study

The objectives of the study are:

(i)   To establish the psychosocial challenges that members of the Manicaland Albino Association are facing in Mutare urban.

(ii)   To establish the attitudes and beliefs associated with oculocutaneous albinism among members of the Manicaland Albino Association in Mutare urban.

(iii)   To explore the extent of stigma and discrimination among members of the Manicaland Albino Association in Mutare urban.

(iv)   To establish the coping strategies being employed by members of the Manicaland Albino Association in Mutare urban.

1.7 Research Questions

The research questions for the study are:

(i)   What are the psychosocial challenges facing members of the Manicaland Albino Association in Mutare urban?

(ii)   What are the attitudes, emotions, behavior and myths associated with oculocutaneous albinism among members of the Manicaland Albino Association in Mutare urban?

(iii)   What are the levels of self esteem among members of the Manicaland Albino Association in Mutare urban?

(iv)   What are the coping strategies employed by members of the Manicaland Albino Association in Mutare urban.

(v)   What recommendations can be drawn from the study results?

1.8 Organisation of the Study.

The study is organised around 5 chapters. Chapter 1 presents the introduction and background to the study. 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 findings. Lastly chapter 5 presents the conclusions, summary and recommendations.

1.9 Conclusion

The chapter discussed the background to the study where an attempt was presented to justify the classification of OCA as a disability. A presentation on the statement of the problem, justification of the study, the aim, objectives, limitations of the study and the study organisation was done.

CHAPTER 2

2.0 LITERATURE REVIEW

2.0.1 Introduction

This chapter reviews the relevant literature on albinism from a global perspective focusing on OCA. The study will discuss psychosocial challenges that include negative beliefs, myths, misconception and attitudes that trigger cases of stigma, discrimination and social exclusion among persons with oculocutaneous albinism. There are two main variants of albinism that have been identified, that is ocular and oculocutaneous (Gronskov, Ek and Nielsen, 2007). Oculocutaneous albinism affects the eyes, skin and hair whilst ocular albinism affects the eyes only (Lund 2005). Oculocutaneous albinism is passed from one generation to another through the autosomal recessive means whilst ocular albinism is variant sex-linked (www.biomedcentral.com).

Medically four types of OCA have been investigated and these are the OCA1, OCA2, OCA3 and OCA 4. Of the types listed OCA1 is regarded as the most malevolent type distinguished by an absolute lack of melanin production (www.ncbi.nlm.gov). The other types exhibit pigmentation accretion over time (www.ncbi.nlm.gov).OCA1 and OCA 2 are the common types of OCA where OCA1 is defined by little or no melanin production because tyrosinase is dysfunctional which is a crucial enzyme required in the melanin production whilst OCA 2 has tyrosinase which produces a red-yellow pigmentation which culminates in sandy coloured hair and light brown irises (www.biomedcentral.com and www.ncbi.nlm.gov).

According to Lund and Gaigher (2002) persons with oculocutaneous albinism have a distinct appearance and symptoms which are conspicuous in the African population. Waugh (2005) pointed out that oculocutaneous albinism is shrouded with various myths and misconceptions which results in stigma and discrimination, resulting in the society failing to accept them. The operational definitions of concepts are elaborated below.

2.1 Operational Definitions of Concepts

2.1.1 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. As highlighted in chapter 1 there are two major types of albinism which are oculocutaneous albinism and ocular albinism (Kagore and Lund 2005).

2.1.2 Oculocutaneous Albinism (OCA)

Geiger et al (2002) stated that oculocutaneous albinism involves the deficiency of pigment in the hair, skin and eyes. Either of the parents has to have the gene for this form which follows an autosomal recessive inheritance pattern, implying that there is one in four likelihood that the baby will be born with OCA. Lund (2001) pointed out that due to the dermatology challenges; persons with OCA are prone to skin cancers if exposed to sunlight. This calls for protective measures like the use of sunscreen lotions, sunglasses and hats. Gaigher, Lund and Makuya

(2002) stated that growth and development of a child with albinism is normal and intellectual development is normal.

2.1.3 Ocular Albinism (OA)

Geiger et al (2002) highlighted that ocular albinism has the same effects in the eyes and the visual pathway as it is in the oculocutaneous albinism. However, the pigment in the retinal pigment epithelium is reduced, and there is usually no clinical consequence in the pigmentation of the skin and hair (Oetting, Brillian and King, 1996).The skin and hair of the person may seem normal.

According to Oetting et al (1996), ocular albinism has two variants based on the inheritance pattern that is the autosomal recessive ocular occurring in both men and women, and the X-linked ocular with symptoms occurring mainly in men. Oetting et al (1996) states that in the X-linked cases, mothers carry the gene and pass it to their sons.

2.1.4 Attitudes

Aiken (2002), Fishbein and Ajzen (1975) posited that an attitude is a predisposition to respond positively or negatively towards a particular idea, object, person, or situation and this influence a person's choice of action. Aiken (2002:201) noted that attitudes have four major components that is *"affective which include emotions and feelings, cognitive which include belief or opinions held consciously, conative which is inclination for action and evaluative which include a positive and negative response to stimuli"*. Persons with oculocutaneous albinism have been exposed to both

positive and negative attitudes from the society and this has determined their levels of self-esteem (Lund et al, 2007).

2.1.5 Stigma, Prejudice and Discrimination

Baron and Byrne (1997) referred to prejudice as a special type of attitude, usually a negative one towards members of a social group .Coleman (1997) is of the point that prejudice also involves beliefs and expectations about members of these groups. Coleman (1997) defined stigma as the holding of derogatory social attitudes or cognitive beliefs that radically changes the way people view themselves or the way they are viewed by others. Coleman (1997) goes on to define discrimination, as the negative actions towards those people.

Miller and Major (2000) posited that stigma and discrimination results in low self esteem leading to depression in the lives of the concerned people. They argue that stigma and discrimination demean the social identity and this leads to depression among the concerned people (Miller and Major, 2000).

2.1.6 Psychosocial

Nieman (2002) viewed psychosocial as a term that emphasises 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). Hence in this context the term views persons with OCA in totality that is within the context of the person and the environment he or she lives.

2.1.7 Self esteem

Robson (1988) asserted that self esteem, in the context of disability, is when a disabled person evaluates his or her capacity to perform in the society. Self esteem is critical on how persons with disabilities value themselves in the society in which they face challenges of adjustment and in some instances are perceived as 'abnormal' (Cusforth, 1951). Robson (1988) pointed out that low self esteem is defined by feelings of inadequacy, social isolation or withdrawal and interpersonal problems. Rosenberg (1965) also defined self-esteem as how a person perceives his or her self worth. Cloninger (2000) posited that self esteem is a sense of positive self worth and it can be measured by various self report questionnaires. High self esteem has various manifestations which include self confidence and being an extrovert and persons tend to report fewer negative emotions and less depression than persons with low in self-esteem (Rosenberg, 1965).

2.1.8 Emotions

Abraham, Gregory, Wolf, and Pemberton (2002) viewed emotions as experiences that include a subjective feeling, a cognitive interpretation, a physical reaction and behavioural expression for example anger, depression and guilt. Emotions are feelings brought about by an individual perception about an experience. Persons with OCA express anger and frustrations due to stigma and discrimination that makes them unequal with others in the society (Richards, 2005). Internalization of these feelings reinforces feeling of low self esteem among persons with OCA (Richard, 2005). Lutha and Blatt (1993) posited that when persons with OCA evaluate themselves negatively, they experience unpleasant emotions like embarrassment, anger and depression.

2.1.9 Coping Strategies

Folkman, Lazarus, Schetter, Delongis and Gruen (1986:993) quoting Lazarus and Folkman (1985) 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 stressful situation, independent of their value and effectiveness"*. A particularly important distinction is between engagement coping, which is aimed at dealing with the presented challenge or related emotions, and disengagement and avoidance coping, which is aimed at escaping the threat or related emotions. Disengagement coping is often emotion focused, because it involves an attempt to escape feelings of distress. Engagement coping includes problem-focused coping and some forms of emotion-focused coping: support seeking, emotion regulation and acceptance. Disengagement coping includes responses such as avoidance, physical and social withdrawal. Durkheim (1915) and Treloar (2000) pointed out that religion plays a critical role in the lives of the oppressed.

2.2 Theoretical Framework

2.2.1 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). Models are ways of translating ideas into practice (Oliver 1990:56). Simpson and Cheasman (2000) rightly observe that understanding of disability is influenced by existing models which are based on widely differing assumptions.

There are various models that include the charity, medical, social and biopsychosocial which seeks to explain disability with some having been advanced from chillingly atrocious to strangely weird ideas; and others offering from *"radical, ideal and empowering to simply idealistic and unattainable conceptions"* (Butler and McEwan 2007:15). 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 behaviour"* (Munsaka 2012:25).This approach has defined various social policies that consider persons with disabilities as charity cases hence it has been heavily criticized.

In this regard the study is to employ the social model of disability to explain the psychosocial implications of persons with OCA.

2.2.2 The Social Model of Disability

Vic Finkelstein is closely associated with the establishment of the social model of disability, though it is worth noting that Oliver simply popularized and consolidated the Union of the Physically Impaired Against Segregation (UPIAS) ideas (Finkelstein, 2001).

Oliver (1996) viewed the social model of disability as a fundamental shift from the medical model of disability that stresses on the functional restrictions in the explication of disability to the emphasis on how society structures disable persons with disabilities.

Charlton (1998) pointed out that regardless of the socio-economic, political and religious nature of the society in which they live; disabled persons are subjected to social oppression and

negative social attitudes that inexorably hurt their personhood and their status as full citizens. Social oppression in turn gives rise to individual and institutional and structural discrimination imposing disabling social, environmental, and attitudinal barriers on persons with disabilities. (Ingstad and Whyte, 1995). Some of these attitudinal barriers manifest themselves as an expression of *"horror, fear, anxiety, hostility, distrust, pity, over-protection and patronizing behavior"* towards persons with disabilities culminating in stigmatization and discrimination (Barton, 1996:8 and King 2005). According to Gleeson (1999) he stated that the idealistic model which is a subset of the social model perceives disability as conceived in the negative attitudes of society towards the impaired body. This implies that disability is defined by the interpretation and relaying of attitudes towards persons with disabilities. Proponents of this model proffered attitude changing policies as a way of fully integrating persons with disabilities in society (Gleeson, 1999).

Charlton (1998) argued that most of the disabled persons have been so psychologically subjugated by the society that their oppression has become entrenched. As a result, they develop what Marx 1884) referred to as *'false consciousness'*, whereby they devalue themselves. This has negatively affected the levels of self-esteem among persons with disabilities.

This social oppression has also resulted in social exclusion of persons with disabilities denying them adequate and appropriate services (Abberley, 1987).This assumption is also highlighted by UPIAS 1976:4 when it stated that the social model of disability is founded upon the premise that disability is something imposed on impairments as a result of isolation and exclusion from the society.

Oliver (1996) pointed out that underlying the notion that disabled people are oppressed is the assumption that all societies are characterized by conflict between two competing groups; the dominant and the subordinate hence in this regard persons without disabilities are the dominant group subordinating persons with disabilities.

A critical tenet of the social model of disability according to Oliver (1996) is that impairments do not cause disabilities, but it is the society that erects barriers on them that result in disability. Oliver (1996) further alluded that it is the way in which social structures work to detach and exclude disabled people from full participation in society. In this regard Finkelstein (2001) argued that the social model of disability challenges the barriers that prevent persons with disabilities from realizing the same level of functioning as non-disabled persons.

Mtetwa (2011) further alluded that impairments are normal in any given society but it is how the society is ordered that triggers disability hence the model calls for the challenging of these structures that creates barriers for the full integration of persons with disabilities. Oliver (1996) does not totally disregard the point that impairments themselves can cause challenges to persons with disabilities. In this respect he argued that individual interventions may be vital in improving the quality of life of persons with disabilities just like any person in the society (Butler and McEwan, 2007).

The social model of disability has led to the identification of people with disabilities and persons with disabilities as the suitable terms (Oliver, 1990). With regards to oculocutaneous albinism this led the researcher to use the terms, persons or people with oculocutaneous albinism

interchangeably .With the advent of the social model there is a need for taking into consideration issues of abuse, negligence, isolation, and marginalization in the lives of persons with oculocutaneous albinism (Butler and McEwan, 2007).

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 (Munsaka, 2012). While material inequality is imperative, this argument has led to a focus that exclusion from paid employment is fundamental to the disablement of people with impairments (Barnes, 1999), yet joblessness only cannot explicate social exclusion.

Critics have questioned the capacity of the model to deal with issues of difference among disabled people and have pointed that it is inadequate (Munsaka, 2012). For example, the social model implies that all disabled people, regardless of particular impairments, are united in the understanding that they all meet exclusion, discrimination and oppression (Munsaka, 2012). In turn Lang (2009:278) warns that *such a position does not recognize that different*
 groups and their respective organizations may not share the same political agenda, nor be subjected to exclusion, discrimination and oppression in the same manner."

Regardless 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 oculocutaneous albinism premising the discussion on the social model of

disability, exposing how the society is socially excluding them and how they are coping with stigmatization and discrimination (Lund, 2005).

2.3 Occurrence of Oculocutaneous Albinism

2.3.1 Global Occurrence

Lund, Puri, Durham-Pierre, King, Brilliant (1997) stated that the occurrence of albinism varies significantly globally due to the diverse founder genes and the challenges associated with differentiating diverse subcategories of albinism (www.ncbi.nlm.nih.gov). The prevalence rates of OCA vary among different tribes for example the Zulu and Tswana in South Africa (Kagore and Lund, 1995). Christianson, Howson and Modell (2006) are of the idea that certain ethnic groups show a higher prevalence as a result of traditional marriage patterns of consanguineous unions.

According to Gronskov, Ek and Nielsen (2007) estimated global prevalence rate of albinism is approximately 1 in 17,000, with Africa having the highest prevalence rates. Christianson et al (2006) indicated that OCA1 prevalence rate is estimated at 1 per 40,000 in the majority populations though rare amongst African-Americans.

 In the United State of America, the prevalence rate of oculocutaneous albinism among whites is estimated at 1 in 36 000. In the secluded groups of the Hopi Indians in Arizona, OCA rates are higher and estimated at 1 in 277 (Kagore and Lund 1995).

The occurrence of OCA3 in Africa is estimated at 1:8500 but this type is isolated among Caucasians and Asiatic populations (www.ncbi.nlm.nih.gov). OCA4 affects about 5-8% of the Germans and an estimated18% of the Japanese (www.ncbi.nlm.nih.gov).

2.3.2 Oculocutaneous Albinism Occurrence in Africa

In Southern Africa the prevalence rate of OCA stands at 1 in 3900 of the population (www.ncbi.nlm.nih.gov).In parts of Nigeria the occurrence of albinism is 1 in 1100 and in South Africa the prevalence rate is 1 in 1800(www.internationalreporters.org).

Lund et al (2007) established that in South Africa prevalence rates among the Tswana are double compared to the Zulu because Tswana encourage marriage between relatives while Zulu discourages it (www.internationalreporters.org). Delport, Christianson, van den Berg, Wolmarans and Gericke (1995) in their study established a birth prevalence rate of 0.66 per 1000 live births of oculocutaneous albinism in a rural area in South Africa. On the other hand Venter, Christianson, Hutamo, Makhura and Gericke (1995) recorded 0.23 per 1000 live births of oculocutaneous albinism in an urban area in South Africa. In Swaziland, the prevalence of the condition ranges from 1 in 1279 (Venter etal 1995).The estimates of oculocutaneous albinism among the Black population in Dar-es-Salaam, Tanzania was 1 in 1429 (Kromberg and Jenkins 1982:384). The Albino Association of Tanzania puts the estimate at 150000 (www.slate.com/articles/news).

2.3.3 Occurrence Rates in Zimbabwe

Estimates for oculocutaneous albinism in Zimbabwe vary. Lund (1996) stated that prevalence rate of OCA2 among the black Zimbabweans stand at 1:4182 and specifically for the Tonga ethnic group it is estimated at 1 in 1000. Kagore and Lund (2005) established that the prevalence of OCA2 in schoolchildren in Harare was found to be 1 in 2833.

A survey of 1, 3 million pupils in Zimbabwe by Lund (1996) established that 278 pupils had oculocutaneous albinism (OCA), implying an occurrence of 1 in 4728, with Harare and Manicaland provinces recording high frequencies. According to Professor Makumbe, approximately 15 000 persons with albinism in Zimbabwe endure stigma and discrimination in the communities they live (www.newsday.com).

2.4 Life Expectancy

Most studies conducted on persons with OCA established that the mean age of respondents is below 30 years (www.biomedcentral.com). In East Central Nigeria, Okoro (1975) established that 89% of the respondents with albinism were in the ages of between 0 - 30 years whilst another study in the same area indicated 77% of the respondents with albinism were under the age of 20 years and in Soweto the mean age stands at 17, 8 years (www.biomedcentral.com). Studies conducted in Cameroon, Nigeria and Tanzania pointed out that there were few persons with albinism above 30 years (www.biomedcentral.com).The Zimbabwe Albino Association in 2002 revealed that person with albinism life expectance is 43 years compared to 57 years for a Zimbabwean (www.internationalreporters.org).

From the above discussions one can see that statistics on the actual number of persons with albinism is not known as shown by different studies generating varying prevalence rates. What is crucial to this study is that persons with OCA exist in various communities and face various psychosocial challenges. This group of persons has been exposed to various forms of institutional and structural discrimination. Comparatively in Zimbabwe, the plight of persons with OCA has not received considerable attention as compared to other vulnerable groups like women and orphans and vulnerable children.

2.5 Social Stigma, Prejudice and Discrimination

Misconstructions and myths about persons with oculocutaneous albinism in various countries of Africa, Zimbabwe included, have culminated in stigmatization and discrimination (Lund et al, 2007).

Coleman (1997) 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. Coleman (1997) pointed out 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. Discrimination results in oppression hence individual might find it difficult to claim their rights (www.ok.org).

Three critical issues have been identified with regards to stigma, and these are lack of knowledge or ignorance, negative attitudes or prejudice and rejecting behaviour or discrimination (Thornicroft, 2006). Goffman (1997) postulated that stigma entails the attachment

of derogatory social attitudes or cognitive beliefs to persons with disabilities. Stigma is a powerful and demeaning social mark that fundamentally changes the way disabled persons view themselves or the way they are conceived by others (Goffman, 1997 and George 2002).

Colman (1997) asserted that the term stigma initially comes from Greece and represents to the physical marks of disgrace and these typically provoke discrimination from the society. These marks were meant to symbolize something strange and appalling with regards to the moral standing of the beholder (Coleman, 1997). These marks signify that the bearer is *'not quite human'* hence the society excludes them (Coleman, 1997:220). Though the body markings are on the decrease, destructive cognitive social markings have emerged that seriously affects the self esteem of the beholder (Coleman, 1997). Coleman (1997: 225) further elaborated that *"stigma can take many forms such as physical and social isolation from family, friends and community, gossip, name-calling and insults, judging, blaming and condemnation and break-up of relationships".*

Stigma leads to lowering of social status among oppressed people and an attack to their inherent worth and dignity. Social rejection is a way in which the society conveys a sense of inadequacy in stigmatized people (Coleman, 1997). This scenario has lead some persons with OCA having low self esteem which militates on their self worth and in some instances trigger emotions like anger, depression and guilt which has a bearing on their health (Abraham etal, 2002 , Miller and Kaiser, 2001).

2.6 Perceived Societal Beliefs and Attitudes

The etiology of oculocutaneous albinism is hardly understood because sometimes the society conceives it around myths and misconceptions (Lund et al, 2007). However, the situation of persons with OCA is more at crossroads in Africa because it stands out in stark contrast to a predominantly dark pigmented population (www.albinism.org.uk).

The following discussion is to elaborate on how stigma, prejudice and discrimination have defined people with OCA and the societal attitudes towards persons with oculocutaneous albinism. Teachers and other children behaviour and attitudes towards pupils with OCA have been shaped around stigma and discrimination (Lund et al, 2007). Lund (1997) established that due to stigma and discrimination children with oculocutaneous albinism are hidden at home instead of being sent to school hence denying them a fundamental human right to education and participation in various societal activities. In Zimbabwe some parents send their children to school as a form of investment in times of old age and invalidity (Lund, 2005). With rampant belief that persons with OCA die at a young age, they might find themselves out of school with preference being on siblings without OCA (McNeil, 1997). This has perpetuated the vicious circle of social oppression and exclusion among persons with OCA (Lund et al, 2007).

Misconceptions on the etiology of oculocutaneous albinism have resulted in some societies treating the condition as contagious. Due to this some people believe that if one shares items like utensils or has any physical contact with a person with oculocutaneous albinism, he or she will also develop the condition (Lund et al, 2007).In his study Douglas (1966) observed that persons with disabilities were avoided by the society as a counter measure hence likewise society may

not be willing to share with someone with OCA. Discrimination to persons with oculocutaneous albinism is exemplified when Makumbe, who has albinism said *,"When I walk into a dining hall or during tea break at workshops, I make sure that everybody takes their food and tea first and wait until everyone has taken their food. There are people who will not share a teaspoon with me and I have learnt to live with that"* (www.newsday.co.zw). He further stated that *"I am also aware that not everybody accepts a handshake from me, so I wait for them to stretch their hands first. There are shops that will tell me openly not to touch anything. But if God made me this way, then it is not my problem"* (www.newsday.co.zw).Lund (1997) established that some pregnant mothers spit on the ground as a counter measure, fearing that the condition might be passed to the unborn child.

Waugh (2005) pointed out that children with oculocutaneous albinism are believed to be a curse and viewed either as being a vengeance for something wrong done previously or as being a victim of witchcraft in the family. Lund (1998) established that these beliefs are predominant in rural areas and this has further socially excluded persons with oculocutaneous albinism as they might be hidden from the public, prohibited from socializing with others and treated as outcasts (King, Summers, Haefemeyer and Leroy, 2005). It is clear that these traditional beliefs and practices are very wrong and are very harmful to the emotional, physical and psychological state of both children and adults with oculocutaneous albinism (Khan, 2005).

Waugh (2005) established that the birth of a child with OCA can trigger gender based violence as the mother will be blamed by the husband, relatives and the society at large. Khan (2005)

stated that lack of information on oculocutaneous albinism has made it a mammoth task for parents, families and communities to explain the condition upon the birth of a child with OCA.

2.7 Teasing and Name Calling

Coleman (1997 established that derogatory and demeaning terminology for persons with oculocutaneous albinism has led to prejudice and stereotypes. This constitutes emotional abuse which has at sometimes affected negatively the self worth and dignity of persons with OCA (Coleman, 1997). These derogatory and humiliating names imply that persons with oculocutaneous albinism are lesser beings (Coleman, 1997 and Hosking 2008). In Kiswahili the name for persons with oculocutaneous albinism is *'Zeru Zeru'* suggesting a double zero or a worthless person while others called them *'mzungu'* meaning 'white man' (NOAH 2007).

NOAH (2007) observed that due to the lack of pigmentation of persons with OCA, the Bamileke people of Cameroon associates them with the sacred world of the dead hence they are referred to as *'meffeu'* meaning *'dead'*. Other titles used include *'fogtab gab'* (white or chicken or *'bwongou'* (strange person) (NOAH, 2007). The reason behind these terms is to portray persons with OCA as not *'humans',* implying that society does not accord them the rights they should enjoy just like any other community member(NOAH 2007).This has resulted in the blatant abuses and killings of persons with OCA.

In Zimbabwe many traditional names are used to refer to persons with oculocutaneous albinism. These include Shona names like *'murungudunhu'*, *'musope'*, or *'jechwe'*, and these names are degrading and further compromise the self-esteem of these persons (Machipisa, 2002).

The Herald of 27 August 2011 reported that children with oculocutaneous albinism are usually the victims of teasing and name calling. The paper reported how a 11 year old boy with oculocutaneous albinism was emotionally and physically abused by three women who had referred to him as *'murungu asina purazi'* (a poor white man without a farm) (www.zimpapers.co.zw). This did not go well with the boy and he protested, further triggering emotional and physical pain as the women responded by saying *'hatirohwe nemualbino'* (we cannot be beaten up by an albino) and proceeded to assault him. Closely linked to this incident, was that of a boy who was likened to a pig by his colleagues (www.zimpapers.co.zw).

2.8 Social Reasons for the Killing of Persons with OCA

Killing of persons with oculocutaneous albinism in East Africa and Southern Africa, especially in Tanzania, have triggered the need for governments to craft protection measures to ensure that their rights and dignity are fulfilled (Lugungulo and Amri 2009). Though persons with oculocutaneous albinism are found all over the world, there is still lack of knowledge on its etiology (www.albinism.org.uk). This has culminated in the insecurity caused by myths and misconception towards persons with oculocutaneous albinism, which, to the extreme, include ritual killings (Lugungulo and Amri 2009).

NOAH (2005) highlighted that the murder and mutilation of persons with oculocutaneous albinism is rounded on the need to take body parts which are used by traditional healers to create charms. It is a widespread belief in Tanzania that charms mixed with body parts of persons with oculocutaneous albinism; especially the hair, genitals, limbs, breasts, fingers, tongue and blood make strong magic potions which cost a fortune (NOAH, 2005). In Tanzania a leg or an arm can

realize between US$1, 000 and US$3, 000 and the killings tend to peak during election times as demand increases for magical portions by politicians seeking election or re-election (www.albinismmfoundationea.com). The above discussion is echoed by Mtetwa (2010) when he pointed out that persons with OCA are perceived to have supernatural powers hence they have been victims of ritual killings.

Lund and Gaigher (2002) observed that the trend has now hit southern African countries with killings reported in Swaziland and Zimbabwe with a belief that the blood of persons with OCA contains supernatural power that bring prosperity and luck (www.albinismmfoundationea.com). Disregard for the human rights of persons with OCA is blatant in Central Africa where they are perceived as sacrificial lambs. Body parts like fingers are also used to make amulets (www.albinism.org.uk). The demand for body parts of persons with oculocutaneous albinism has resulted in inhumane attacks perpetrated against them (www.albinismmfoundationea.com).

The belief that persons with OCA do not live long has witnessed the callous killing of infants with OCA at birth and this is an unacceptable total disregard to their constitutional right to life (www.albinism.org.uk).

The *'death myth'* , a belief that people with oculocutaneous albinism do not die a natural death but just disappear in the bush, is widely perceived in South Africa (Lund and Gaigher, 2002:390). Cases have been reported that if a person with oculocutaneous albinism passed on at home, high chances are that person is not given a proper burial as it is thought that the person did not follow the right way to the gods (Kromberg, 1992). Infanticide and kidnappings where

children with oculocutaneous albinism are suddenly removed and are seldom seen dying naturally solidifies this *'death myth'* (Lund and Gaigher, 2002:390).

2.9 Employment and Oculocutaneous Albinism

Persons with oculocutaneous albinism find it difficult to secure employment due to the myths and misconceptions linked with the condition (www.albinism.org.uk). These myths and misconceptions have affected negatively persons with oculocutaneous albinism access to education hence affecting their competitive edge when it comes to secure employment. Professor Makumbe highlighted that only a few of persons with oculocutaneous albinism have made it academically in life (www.newsday.co.zw).

In Zimbabwe there is an almost complete absence of people with oculocutaneous albinism in the catering industry as there is a widespread misconception that oculocutaneous albinism is infectious (www.newsday.co.zw).The Herald of 27 August 2011 reported that numerous skin cancers present a *'horrific'* appearance and the condition is often misunderstood to be contagious (www.zimpapers.co.zw). As a result persons with oculocutaneous albinism often face isolation and exclusion from group activities, for example at workplaces (www.zimpapers.co.zw). The paper went on to give an example of Tariro Mazambanio, who, regardless of being suitably qualified, was deprived of a job by a leading supermarket because *'she would put off customers'* (www.zimpapers.co.zw). Allen (2010) also asserted to the challenges of stigma and discrimination faced by persons with OCA when looking for employment.

2.10 Knowledge of OCA by Children with the Condition.

In her study Lund (2001) established that 50.7% of the respondents failed to explain the condition of their skin and hair, 10.9% of the respondents were able to correctly attribute their condition to lack of melanin production and that it is passed through genes, 13.8% of the respondents attribute it to God's will or choice and 9.4% gave wrong statements. This is a clear sign that there is a knowledge gap when it comes to the etiology of OCA. Lund (2001) established that the most frequent misconception was that those with OCA do not have the top layer of skin. The study also established other myths like the belief that if someone emotionally abuses a person with OCA she will give birth to a baby with the condition and also the belief that the mother had eaten something prohibited during pregnancy (Lund, 2001). Lund (2001) also established that few respondents attribute OCA to witchcraft. These myths have created ambiguity on OCA and the society has them to justify their abuse (Waugh, 2005).These abuses associated with OCA have led to emotional torture for persons with OCA (Waugh 2005).

2.11 Perceived Attitudes of Peers and Teachers at School

Lund (1997) pointed out that pupils with oculocutaneous albinism face the challenge of being pointed and laughed at by other pupils resulting in low self-esteem among them. Difficulties faced by persons with OCA at school are that they have visual impairment hence they have challenges in reading and focusing on the chalkboard. In some cases the situation is worsened by teachers who make them sit at the back of classrooms, far from the chalkboard and if they complain they are subjected to emotional abuse (Kromberg, Zwane and Jenkins, 1987).

Name calling and teasing by peers is a major challenge facing pupils with oculocutaneous albinism (Lund, 1997). Ancient societies named something so as to take control of it. Lack of knowledge by other pupils have increased cases of name calling, teasing and insensitive language (NOAH, 2005).

Pupils with oculocutaneous albinism are insulted with demeaning names such as *'Santa Clause',* *'whitey'*, '*Fluorescent face'* and *'District Officer'* and these negative attitudes have led to the dropping from school by pupils with oculocutaneous albinism (Romenesko, 2005:1).

Kromberg et al (1987) established that pupils with oculocutaneous albinism are shunned by their peers who are reluctant to sit near, eat or play with them. This has a negative impact on their self-esteem especially for the child who is being deprived of the critical physical expression of love and care at a time they will be trying to establish group interaction and acceptance (Kromberg et al, 1987, Brown and Mankowski, 1993).

Lund (2001) highlighted that Zimbabwe's pupils with oculocutaneous albinism have been incorporated into the mainstream education and this inspires and support constructive attitude towards persons with OCA.The system contributes to an enhanced self-image and self-worth of the pupils with oculocutaneous albinism (Lund and Gaigher, 2002).

Christianson et al (2006:25) highlighted that "*photophobia, nystagmus, lack of stereopsis, and strabismus"* have resulted in pupils with oculocutaneous albinism often being left out of extracurricular activities such as sport or gardening. According to Lund and Gaigher (2002:365)

such social exclusion of pupils with oculocutaneous albinism has manifested in the exclusion from activities that encourage cognitive and perceptual motor development.

Visual challenges have affected the academic progress of most pupils with oculocutaneous albinism hence they end up dropping out of school as they might be seen as failures, and eventually seeking disastrous menial outdoor occupations like farming where prolonged exposure to the sun is a threat to their health (Lund, 2001).

2.12 Oculocutaneous Albinism and Self-esteem

Gaigher et al (2002) is of the idea that the family positive or negative reactions have a profound effect on how the society responds to persons with oculocutaneous albinism .This implies that if persons with oculocutaneous albinism are nurtured in environments where they are regarded and treated as stereotypes and not as individuals they will be less assertive feel lonely and timid hence their low self-esteem (Machipisa, 2002, Jordaan and Jordaan, 1998).

Therefore, a societal response sometimes determines how children view their own self-esteem (Lund, 1996). Persons with oculocutaneous albinism have a tendency of isolating themselves and as such, their self-esteem is gradually eroded in their developmental process (Geiger et al, 2002). Hence, Ezeilo's (1989) and Small (1998) findings indicated that persons with oculocutaneous albinism have weaker and less assertive personalities leading to self blame.

2.13 Marital Challenges

Mostly in developing countries women and girls with oculocutaneous albinism have been exposed to ritual defilement and rape and this practice is fuelled by the myth that having sexual intercourse with a woman with OCA can cure HIV and AIDS (Machipisa, 2002). This heinous practice has exposed the victims to HIV infection which compounds their health and psychosocial condition resulting in the increase likelihood of opportunistic infections like cancer and sexually transmitted infections (Baker et al, 2010). Defilement and rape are infringements on women's rights and dignity as enshrined by various laws and policies of different countries (www.albinismfoundationea.com).

Females with oculocutaneous albinism exposed to sexual violence suffer a case of compound tragedies (Lund, 1996). Firstly, women have to fight for their rights in a predominantly patriarchal society. Secondly, having oculocutaneous albinism entails stigma and discrimination from birth which may condemn them to a life marked by high levels of poverty and oppression hence low self esteem (Mohanty, Tolpade, Russo and Torres, 1981).

According to Waugh (2005), stigma and social discrimination of persons with oculocutaneous albinism cuts across various spheres of their lives which includes the marriage institution, where persons with oculocutaneous albinism have been denied the right to start their stable families. The marriage institution among Africans is critical as it carries with it aspects of respect (Gelfand, 1994). Waugh (2005) went on to state that this is in stark contrast with pigmented persons who find it fairly easy to establish partnerships, while those with oculocutaneous albinism will remain single or are in a separation due to negative cultural beliefs. In some

instances the in-laws may refuse to sanction the union resulting in a separation. These marital challenges affects both men and women with OCA, but women are affected more (Waugh, 2005). Machipisa (2002) pointed out that in some communities there is a strong belief that oculocutaneous albinism is a product of inbreeding or racial mixing. Inbreeding and extra marital affairs are serious offenses in many societies; hence the mother and child may find themselves unwelcomed in the society, leading to divorce (Machipisa, 2002).

The Herald of 27 August 2011 published a story of Ms Loveness Mainato who was subjected to stress and trauma after giving birth to a child with oculocutaneous albinism. The birth of the child triggered endless episodes of all sorts of abuse from her husband and relatives (www.zimpapers.co.zw). She was accused of being a prostitute and practicing witchcraft which resulted in the siring a child with OCA (www.zimpapers.co.zw).

The situation for her was made worse when the husband decided to have a child with their maid. The situation was further compounded when Loveness gave birth again to a child with oculocutaneous albinism which led to her being divorced and her husband left for Botswana. Out of frustration the husband did not even name the child claiming that he was not comfortable with being associated with children with oculocutaneous albinism (www.zimpapers.co.zw).

The above situation motivated Ms Mainato to address issues affecting persons with albinism by forming the Albino Charity Organization of Zimbabwe (Alcoz) in order to fight against discrimination of people living with the condition (www.zimpapers.co.zw).

The Herald of 27 August 2011 reported that the Albino Charity Organization of Zimbabwe recorded 33 cases of members that have divorced because of pressure from relatives or rejection by their spouses in Chitungwiza (www.zimpapers.co.zw).

A study carried out by Machipisa (2002) established that more than 63% of children with oculocutaneous albinism in Zimbabwe are from broken homes. Most of the cases were of fathers abandoning their families upon the birth of a child with OCA, and if they opted to stay with their families, the mother and the child are exposed to all forms of abuse (Machipisa, 2002). The child would be stigmatised and discriminated against because he or she would be perceived as having brought shame to the whole family (Machipisa, 2002). The Herald of 27 August 2011 also reported that most females with albinism stay unmarried because men avoid them for fear of having albino children with them (www.zimpapers.co.zw).

Having left as single mothers without a reliable source of income and support, mothers of persons with OCA may face huge difficulties with childcare and custody and they end up neglecting their children (Machipisa, 2002). Nevertheless some parents or mothers recover from the initial shock and accept a child with OCA and treat him or her like any other family member (NOAH, 2007).

2.14 Conclusion

This chapter has deliberated the key issues concerning the society and stigmatization of albinos particularly the social stigmatization and discrimination. Issues of gender based violence against persons with oculocutaneous albinism and massacre were also covered during the discussion.

The literature above shows that persons with oculocutaneous albinism within the African context are taunted from cradle to grave (Okoro, 1975). Their self-esteem is low and the perceived societal attitudes towards them are negative as well. The social model of disability and the self-esteem theory discussed above have explained the social aspects of oculocutaneous albinism and how persons with the condition value themselves. The perceived attitudes and beliefs of the community towards persons with oculocutaneous albinism have fuelled incidences of stigma, prejudice, stereotyping and discrimination in Zimbabwe.

CHAPTER 3

3.0 METHODOLOGY

3.0.1 Introduction

This chapter focuses on the study area setting, research methodology employed by the study which includes the data collection methods, tools, sampling techniques and sample size, procedures used to collect data, and methods for data analysis.

3.1 The Study Area Setting.

This study was conducted among the Manicaland Albino Association members in Mutare urban. The Manicaland Albino Association was founded in May 2010 in an endeavor to educate the society on albinism and demystify beliefs that the condition is associated with (www.tigweb.org). The formation of the association was spearheaded by Bishop Patrick Mutume of the Roman Catholic Church. (www.thezimbabwean.co/news). According to the register, the MAA has a total membership of 130 persons with oculocutaneous albinism and it is critical at this point to note that this figure represents those persons who are aware of MAA and the figure might be higher.

The vision of the association is to see liberated and empowered persons with albinism who are active members of the society. In this regard MAA seeks to promote dignity, equality, empowerment and advancement to disadvantaged persons with albinism. (www.thezimbabwean.co/news).

The organisation also provides an interactive platform for those living with albinism as well as their immediate families where they meet with others to share experiences and motivate each other through the Parent Support Group (www.tigweb.org).

The organisation also mobilizes resources on behalf of its members in the form of protective clothing, sunscreen lotions, umbrellas, after sun creams, school fees and uniforms, food, blankets and clothes (www.thezimbabwean.co/news).

The organisation is headquartered in Mutare urban .The city has a population which is predominantly Shona with the majority of them speaking the Manyika dialect. According to the 2012 preliminary census data, Mutare has a population of 188 243 (www.zimstat.co.zw).

The economic decline between 2000 and 2008 due to economic mismanagement, governance issues and the loss of international support did not spare Mutare as many companies closed and most people became engaged in informal business (www.thezimbabwean.co/news). The economy is diversified but biased toward agriculture and mining, which accounts for a big chunk of the foreign currency earnings. Mutare's socio- economic status has been buoyed by the mining of diamonds in Marange (www.thezimbabwean.co/news).

Mutare urban is home to many religions and denominations. There is Christianity, Muslim and African traditional religion. Christian religion denominations include the Roman Catholic, Anglican, Seventh day Adventist, Apostolic Faith Mission, Zimbabwe Assemblies of God, Apostolic sects among others (http://pastoralcareservices.net).

Religious organisations that offer support to disabled persons include Youth Alive, Pastoral Care and Counseling Service among others. Other non-religious organisations offering help include Mercy Corps, Loden lodge, Manicaland Albino Association (http://pastoralcareservices.net).

Despite its tropical location, the city has a temperate climate with an average annual temperature of 19 °C (http://en.wikipedia.org). The coldest month is July with a minimum temperature of 6 °C and maximum temperature of 20 °C. The hottest month is October with minimum temperatures of16 °C and maximum temperatures of 32 °C) (http://en.wikipedia.org).

Mutare urban has a number of both primary and secondary schools which are either boarding or day schools. There are 10 secondary schools and 16 primary schools (http://mutarezimbabweafrica.blogspot.com). Most of them are day schools which imply that pupils walk to school. In some instances students walk long distances to school.

3.2 Research Design

Qualitative and quantitative methods were triangulated in this study. Triangulation is defined as a technique for collecting, analyzing and mixing both quantitative and qualitative data of the research process within a single study so as to comprehend a research problem holistically (Creswell, 2002).

The triangulation technique was employed to ensure validity of results. Various data collection methods were used for the qualitative data. These included, key informant interviews and focus group discussions for the qualitative data. For the quantitative data it included semi-structured

questionnaires and Rosenberg's Self-Esteem Scale .The data collection tools were pre-tested so as to cross-check them for reliability and validity of research findings.

3.3 Target Population

Records held by the Manicaland Albino Association indicate that there are 130 persons with oculocutaneous albinism in Mutare urban and this number constituted the target population.

3.4 Sampling Technique

The study utilised the probability and non probability sampling methods to select the respondents and participants of the study. Simple random sampling technique, a probability technique was employed to select 30 respondents for the study. A membership list with 130 members from the Manicaland Albino Association was utilized as the sampling frame from which30 respondents with oculocutaneous albinism were selected for the study. Each name on the register was assigned a number and the numbers were put in a hat to determine the 30 respondents to be selected. This constitutes 23% of the targeted population.

 A purposive sampling, a non probability sampling method was employed to target 3 key informants and 10 participants for the 2 focus group discussions.

3.5 Data Collection Methods

3.5.1 Interview Schedule.

The interview schedule was administered to 30 persons with oculocutaneous albinism. Information collected helped in quantifying findings from the focus group discussion and key

informant interviews. The questionnaire sought to establish the demographic data of the participants, knowledge on oculocutaneous albinism, their self-esteem and the psychosocial challenges they face. The questionnaire also sought to establish the incidence of stigma and discrimination towards persons with oculocutaneous albinism.

3.5.2 Rosenberg Self-Esteem Scale

Rosenberg (1965) propounded that the self esteem scale is a ten item Likert scale with items answered on a four point scale, ranging from strongly agree to strongly disagree. This tool was administered to the 30 sampled persons with oculocutaneous albinism. The Rosenberg self-esteem scale was developed to measure persons with OCA self-worth and self-acceptance. The score ranges from 0-30. Scores are calculated as follows:

For questions 1, 2, 4, 6, and 7 on the scale were scored as follows;

Strongly agree = 3

Agree = 2

Disagree = 1

Strongly disagree = 0

For questions 3, 5, 8, 9, and 10 on the scale were scored as follows (which are reversed in valence);

Strongly agree = 0

Agree = 1

Disagree = 2

Strongly disagree = 3

Scores between 15 and 25 are within normal range; scores below 15 suggest low self-esteem (Crandal1973).

3.5.3 Focus Group Discussions (FGDs)

With the utilization of the focus group discussion guide, 2 focus group discussions were conducted consisting of 10 participants, 5 of them were males and 5 were females in both cases. The first one was conducted with 10 care facilitators and the other one with 10 persons with oculocutaneous albinism .These focus group discussions were conducted to assess people's knowledge, attitudes, emotions and challenges as they relate to oculocutaneous albinism. The FGD sought to clearly understand what psychosocial challenges persons with oculocutaneous albinism face and come up with recommendations on how best they can be tackled. From these focused discussions 2 unique cases were further explored using the same discussion guides to come up with case studies.

3.5.4 Key Informant Interviews (KII)

An interview guide was employed to collect data from key informants .These include the Manicaland Albino Association Chairperson, the Mutare Department of Social Services Head, and National Association of Non-governmental Organizations Mutare Coordinator so as to have an assessment of how they comprehend the psychosocial challenges faced by persons with oculocutaneous albinism. The interviews also sought to establish what these key informants perceived of support being given by the government and the donor world to persons with oculocutaneous albinism.

3.6 Data Analysis

Qualitative data collected from the key informant and focus group discussions were transcribed and where necessary translated to English. The data was sorted, categorized and coded. After the data had been sorted, it was then organized into coherent categories that summarize and bring meaning to the data collected. The qualitative data transcripts were then read further and analyzed, searching for key words, themes, phrases, terminology as well as ideas that would help to answer the research questions. Quantitative data were manually cleaned and analyzed using Microsoft excel.

3.7 Limitation of the Study

The research was conducted on a small population size, hence to generalize the results for larger groups; the study should have involved more participants at different levels.

3.8 Ethical Considerations

Vadum and Rankin (1998) stated that ethics are regulations that propose expectations about the most proper behavior towards experimental subjects .The following ethical considerations were adhered to:

• **Confidentiality:** It is an explicit or implied assurance by a researcher to a participant in a research whereby the participant is confident that any information provided to the researcher cannot be attributed back to that respondent. Hence information from this study was kept confidential. Pseudo names in all case studies were used to protect the respondents' identities.

• **Consent:** Participants right to self determination was respected. The aim of the research was explained to them. The researcher clearly articulated to the participants that there was no material or monetary gain by being involved in the research, but the document can be used for policy guidance and advocacy work in various communities. Respondents that were not comfortable to discuss issues pertaining OCA were exempted from the research and those who participated agreed to a statement of consent to confirm their understanding of the study as well as their readiness to participate.

3.9 Conclusion

This chapter has discussed the research design and methodology employed by the study. Effort was made to outline the sampling technique employed, the sample size, data collection methods and how the data was analysed. This chapter also presented the study area setting and the research ethics observed.

CHAPTER 4

4.0 PRESENTATION AND DISCUSSION OF FINDINGS

4.0.1 Introduction

This chapter will present the data collected using a range of tools and analyse it to deduce meaning. Presentations are done in the form of tables, graphs, pie charts, and, in some instances, verbatim excerpts of participants' views and responses to questions. In this analysis, the study keeps in perspective the aim, objectives and research questions presented in chapter three. Qualitative and quantitative findings are to be presented concomitantly. Some of the qualitative results are presented in the form of descriptions of themes that emerged from the analysis of the information gathered through focus group discussions and key informant interviews.

The findings and analysis will also be related to the body of knowledge presented in the literature review in order to find out whether the data concurs with what is already known as well as the new insights it reveals on the issues in question. The chapter begins by presenting the demographic information   of the respondents and proceeds to elaborate on how these demographic aspects predispose the respondents to psychosocial challenges related to the subject under study.

4.1 Demographic Information

The respondents' demographic information to be presented and analysed are the level of education, sex, age, employment status, marital status and religious affiliation.

4.1.1 Distribution of Age Range and Sex

The study findings on age range and sex distribution are illustrated in figure 1 below:

Figure 1: Distribution of Respondents by Age range and Sex

N=30
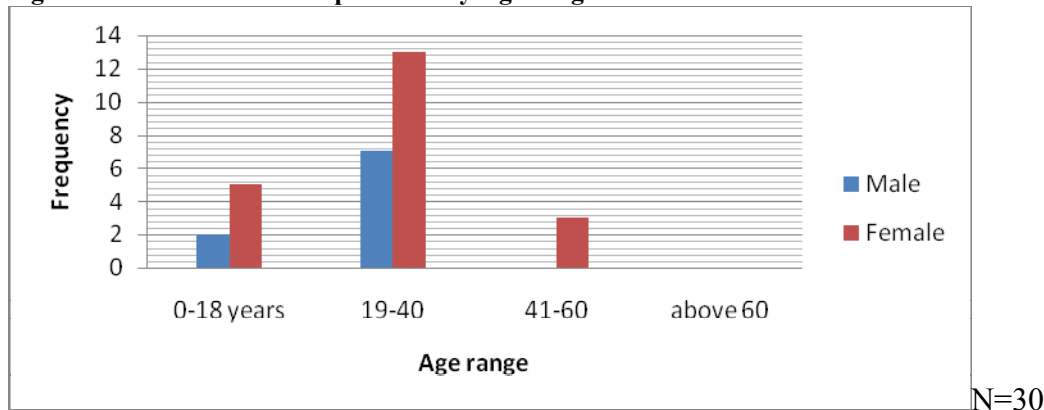
Figure 1 above illustrates that 7 (23%) respondents were in the age range of 0-18 years, 20 (67%) of the respondents were in the range of 19 to 40 years, whilst 3 (10%) were in the age range of 41-60 and no respondents were above 60 years. The mean age of the respondents' was 33 years. Figure 1 above also shows that 21 (70%) female respondents and 9 (30%) male respondents. As illustrated by figure 1 above, the study also established that the majority of the females 13 (43%) were in the age range of 19 to 40 years whilst the majority of the males 7(23%) were also in the same age range. The youngest respondent in the study had13 years and the oldest had 45 years. The study did not have respondents of more advanced ages probably because as argued by the Zimbabwe Albino Association, a person with albinism's life expectancy is 43 years compared to 57 years for a person without the condition (www.internationalreporters.org). This was largely attributed to a low quality of life being experienced by persons with OCA resulting in early deaths.

Lund et al, (1997) argued that some of the causes of early deaths among persons with oculocutaneous albinism are skin cancers which are not properly managed mainly due to poverty which is compounded by stigma and discrimination. Lund et al, (1997) indicated that stigma is presented in the form of negative attitudes towards persons with OCA which results in them not accessing medical treatment on time. One of the key informant highlighted that they once dealt with a case where a parent was hiding her child with OCA to avoid the negative beliefs associated with the condition hence in the process denying the child his right to access medical care. One of the key informants also pointed out that there is no facility for early skin cancer detection and treatment in the country and due to the high costs of radiotherapy and chemotherapy persons with OCA are dying of skin cancer at an early age. Makumbe (2010) being quoted in the Newsday press buttressed the above point when he also argued that most persons with albinism also die at a young age due to depression induced by stigma and discrimination (www.newsday.co.zw).The above assertion also concurs with what Miller and Kaiser (2001) postulated, that stigma has negative health effects on persons with OCA.They argue that stigma and discrimination compromise the immune system and heart activity which make persons with OCA susceptible to illnesses (Miller and Kaiser, 2001).

From the above discussions one can see that the society is not being sensitive to the needs of persons with OCA.

4.1.2 Marital Status

Persons with oculocutaneous albinism find it difficult to establish marriage partnerships due to the myths and misconceptions fuelled by a society that is yet to be fully educated and appreciate

the condition. Of the 30 respondents, 13 (43%) were single, 5 (17%) never married, 5 (17%) were married and 6 (20%) separated with their spouses. The partners of 3 married respondents did not have oculocutaneous albinism whilst 2 couples both partners had oculocutaneous albinism. Table 1below illustrates the above-mentioned findings.

Table 1: Distribution of Respondents by Marital Status and Sex.

Marital Status	Male	Female	Total	%
Single	5	8	13	43
Never Married	1	4	5	17
Married	2	3	5	17
Divorced	0	1	1	3
Separated	1	5	6	20
Widowed	0	0	0	0
Total	9	21	30	100

N=30

These above findings concur with what Gaigher, Lund and Makuya (2002) established in their study. They pointed out that choosing a marriage partner is a serious challenge for persons with oculocutaneous albinism, pointing out incidences of stigma and discrimination as causal factors (Gaigher, 2002 etal).The study established that this challenge is mostly felt by women with OCA as 10 (33%) of the female respondents indicated that they had separated or divorced or never married. A female participant in the FGD in an emotional outburst out said:

"Ah zvekuroorwa kwatiri dzimwe nguva zvinonetsa nokuti varume vacho vanenge vachida kuexperimenta kuti takamboita sei, vobva vatisiya"(loosely translated to mean that marriage is sometimes difficult for women with…….....albinism because men just want to experiment and thereafter forsake them).

Findings from the focus group discussions highlighted that the marital status of being single, never married, divorced or separated pose some psychological challenges which include, being powerless, hopeless, lack of identity and loss of confidence especially among women because they will be the target of blame and ridicule by the society. This sentiment was expressed by one of the participants who said:

"I wish I could find someone who really loves me and understands my condition. In life one needs an intimate friend with whom you share your joy and sorrows someone who will be your pillar of hope. You require someone to share your life's challenges, rewards and sorrows with, a person who actually knows what you are going through and feels the same way too. ...also people will not respect me even though I am old because they say I am not married hence they call me by my first name"

Geifand (1984) is of the view that marriage is part of a social institution responsible for determining and guiding peoples' identities, perceptions, aspirations, and conduct. This is critical in the Shona culture whereby being in a marriage especially motherhood brings with it respect and dignity. Results from the focus group discussions with persons with OCA established that 100% of the respondents agreed that marriage is a conduit for the expression of love and attention. But nevertheless the study established that some persons with OCA are missing out on this opportunity.

From the above discussion one can deduce that persons with OCA cherish the social experience just like any other person in the society, but the society is socially excluding them from enjoying the benefits of a marriage institution. This is in tandem with what Gleeson (1999) postulated with regards to the structuralist framework of the social model of disability. Gleeson (1999) argued that social phenomena such as economic, cultural or political systems or institutional practices can be barriers to persons with disabilities. Oliver (1990) also supports the idea that disability is

socially constructed through the actions of society in presenting barriers and structures that limit the ability of persons with disabilities to function *'normally'*. Such barriers also limit the ability of such persons to access the opportunities, privileges and resources in society. The study established that negative societal attitudes towards person with OCA have given rise to cases of separation, divorce and being single.

As presented in the first case study below, women with OCA are deserted by their husbands upon the birth of a child with OCA. As illustrated in figure 2 below, the study established that 80% of the respondents had female household heads whilst 20% had male household heads.

Figure 2: Distribution of Respondents by Sex of the Head of Household.

N=30
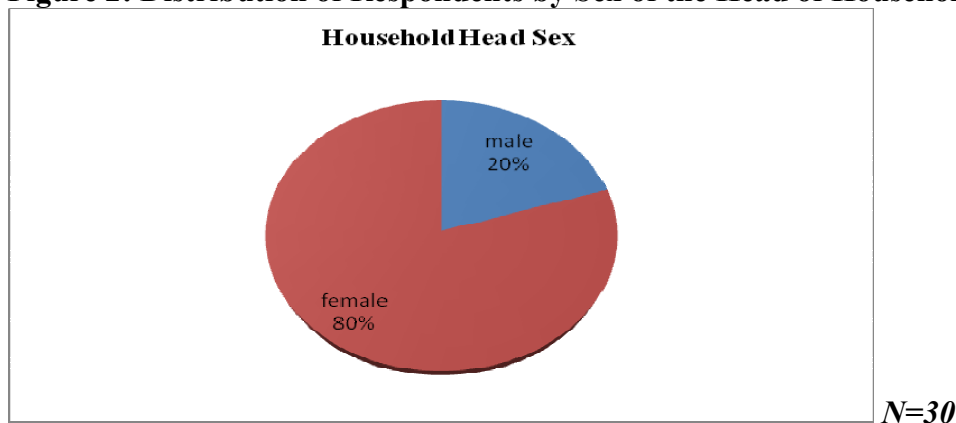
Results from the focus group discussions established that this scenario is due to the negative attitudes of the society that culminate in stigma and discrimination that has resulted in more female headed households taking care of a child with OCA. Most of the respondents agree that usually it is the woman who suffers most upon the birth of a child with OCA, as the husband will expose her to all sorts of abuse, and not to be outdone the relatives and the society also puts the blame on the woman, basing their arguments on myths and misconceptions. This results in the

men abandoning their families and to start new lives somewhere else. The findings are consistent with the assumptions of the radical feminist theory which states that men as a social group have a desire to control women and organize society around oppression (Mohanty, Talpade, Russo, and Torres, 1991).

The case study below illustrates the marital challenges faced by married women with oculocutaneous albinism.

Case Study 1 Belinda - 40 years old

Belinda is a 40 year old female who had been happily married for 20 years. Problems started when she gave birth to a baby boy with oculocutaneous albinism. The husband started to emotionally and physically abuse her. The husband argued that the child was not his since it was something new in their lineage. Belinda was accused of engaging in extra marital affair with someone of light skin to which she vehemently denied. He did not even name the child and up to this day the child does not have a birth certificate .One day when the wife was away, he just packed his bag and left home to start a new life elsewhere. When Belinda realized that she was going to care for the child alone she was distraught and sought help from the church and other fellow mothers with children with OCA where she received counseling.

In concurrence with the above findings, Machipisa (2002) in his study established that the birth of a child with OCA often causes conflicts in families, and sometimes lead the fathers to reject the child or abandon their families. His study findings were supported by a survey of the Zimbabwe Albino Association which showed that most of the people with albinism (63%) were from unstable homes (Machipisa, 2002).

The study also established that males with OCA are in a better position to negotiate a relationship with any partner of their choice. These findings point to the gender dynamics when it comes to the marriage institution. This was evident when one male participant with oculocutaneous albinism said:

"...for me I can date any girl I see attractive, but for my fellow sisters the room for choice might be restricted".

This was in contrast to the question directed to the care facilitators whether they are comfortable with their daughter without OCA marrying a husband with OCA. Most of the participants indicated that they will prefer their daughters to be married by someone without OCA whilst a few indicated that they are comfortable with husbands with OCA. One participant had this to say:

"... i mukwasha zvekuti mwana vangu aroorwe nemualbino zvinonetsa" loosely translated to mean, it is quite challenging for my daughter to get married to someone with OCA.

The study raises the concern that males with oculocutaneous albinism at times face challenges in establishing marriage relationships.

From the membership register presented to the researcher it was established that 80% of the members are women. From the focus group discussions the participants also brought a point that some female with OCA out of desperation (because age mates are getting married) rush into a relationship without thoroughly checking the personality of the intended spouse and they end up being sexually exploited. Though there is an emphasis nowadays by the medical practitioners to

get tested for HIV before starting a family, results from the study established the contrary. One female respondent with OCA indicated that she will not pester her future husband for an HIV tests least he will terminate the relationship. This state of affair exposes persons with OCA to HIV and AIDS.

4.1.3 Religious Affiliation

The study sought to identify the denominations to which the respondents' were affiliated, for the purpose of determining how the norms and belief in the churches could influence the life-experience of persons with oculocutaneous albinism. Table 2 below illustrates the distribution of respondents by denomination and se.Table 2 below shows that 16 (53%) of the respondents are affiliated to the protestant churches, 6(20%) are affiliated to Pentecostal churches whilst 8 (27%) belong to the Apostolic sects.

Table 2: Distribution of Respondents by Denomination and Sex.

Religion	Male	Female	Total Frequency	Total %
Protestant	7	9	16	53
Pentecostal	1	5	6	20
Apostolic	1	7	8	27
African Traditional	0	0	0	0
Others	0	0	0	0
Total	9	21	30	100

N=30

The study established that religion as a social institution has raised hope for persons with OCA.The study established that 100% of the respondents had a strong religious background as they were affiliated to various denominations which include Anglican, Roman Catholic, African Apostolic Mission, Zimbabwe Assemblies of God, Latter Day Saints, Seventh Day Adventists, Methodist, Masowe Echishanu, and Zion Apostolic. On being probed on why they attend church, 100% of the respondents indicated that the church is a source of hope where issues of stigma and discrimination can be addressed hence reinvigorating the strength to face a hostile society. Treloar (2000) stated that this is possible due to norms and morals that need to be observed by church members that will ultimately influence the attitude of the community towards persons with OCA. To support this one participant from the focus group discussion commented that:

"The social teachings of the Catholic Church place value on all people and this really touched me. For example, teachings on human dignity, the common good, subsidiarity and solidarity motivated me to join the church".

These findings also support Smith's (1990) view that solidarity advocates that people need to help and support one another and devoted to the common good and this entails realizing the circumstances that make it probable for all people to come to their full potential. Though these are social teachings of the Catholic Church, its provisions are found in other churches.

From the study it was established that the church plays a critical role in the lives of persons with OCA, accounting for 50% (15) of the total help received ranging from counseling (2), cash (4) and material (9). The point is illustrated by the case study below:

Case study 2

Sharon is a 25 year old young woman with OCA. She resides in Sakubva high density suburb where she grew up being teased by other children and even some adults. Her parents are devout Christians who always took her to church every Sunday. It is at church that she began to make friends with non OCA children and they always defended her when other children teased her. Upon being labelled by other children she reported that she found solace in the words of the local pastor who always pointed out that God created mankind in his image so we are equal before God. Sharon's parents also alluded to the point that the church also chipped in with protective hats and lotions for their daughter.

The role of religion in this study also concurs with what sociologists like Durkheim (1915) and Marx (1844) propounded. Durkheim (1915) pointed out that religion, through rituals, plays a critical role in bringing together members of a particular religion. Durkheim (1915) argued that religion functions to unite society's members by making them assert their common values and beliefs frequently.

The importance of religion is also alluded to by Marx (1844:1) who asserted that religion *"is the sigh of the oppressed creature, the heart of a heartless world, just as it is the spirit of a spiritless situation. It is the opium of the people"*. According to Marx (1884) religion teaches believers to agree to their present situation in life, no matter how bad, while looking forward for happiness after life. Marx (1844) held that religion served as a refuge from the severity of everyday life and domination by the influential. Treloar (2000) pointed out that religion is critical to the emotions of man in times of his sufferings and disenchantment. In this way religion gives release from sorrow and release from fear hence the ability to bear his frustration and integrate his personality.

4.1.4 Education and OCA.

Visual impairment is the primary challenge for persons with OCA, affecting their education and socialization. The question on the level of education was asked to determine whether the level of education could influence the respondents' life-experiences. The study established that 8 (27%) respondents reached tertiary education, 11 (38%) indicated that they have reached secondary level whilst 1 (3%) indicated that he never attended school. It emerged from the focus group discussions that the level of education of the respondents influenced their life-experience. Respondents with primary education were finding it difficult to articulate issues as compared to

those drawn from secondary and tertiary level. For example on being asked what really causes

OCA; one participant attributed the condition to witchcraft as evidenced by the following

excerpt:

"I think my condition is caused by witchcraft. People are jealousy out there especially relatives".

Table 3 below illustrates the educational levels by sex.

Table 3: Distribution of Respondents by level of Education and Sex.

Educational level	Male	Female	Total frequency	Total %
Never attended school	0	1	1	3
Primary	2	8	10	33
Secondary	3	8	11	37
Tertiary	4	4	8	27
Total	9	21	30	100

N=30

Education is critical in the development of the human resource, improving economic

performance, and increasing people's capabilities and choices. The study established that social

barriers have resulted in some persons with OCA not attending school or dropping out of school

at primary level seriously affecting their capabilities and choices in a capitalistic economy, where

the poor have to struggle to make ends meet. One of the key informants highlighted that though

the government has come up with measures like the Basic Education Assistance Module

(BEAM) to help vulnerable children, it is not reaching all children with OCA. The key informant

further elaborated that children with OCA may be discriminated and not benefit from BEAM.

These issues are explained by the social model of disability when it states that institutions can be barriers in the lives of persons with disabilities. These findings are consistent with UPIAS (1976:14) definition of disability; *"the disadvantage or restriction of activity caused by a contemporary social organisation which takes little or no account of people who have impairments and thus excludes them from the mainstream of social activities".*

4.1.5 Employment and OCA

Due to the challenges faced at school which includes name calling and discrimination few persons with oculocutaneous albinism make it to tertiary level hence limiting their chances of being gainfully employed especially in the formal system. Even upon attaining tertiary qualifications persons with OCA find it difficult to enter formal employment due to the reluctance of the employers to employ them. Allen (2010) conducted a research on employment opportunities for persons with OCA, and her findings pointed out to the discrimination experienced by persons with OCA when looking for a job. One participant in the focus group discussion said that,

"...though I was shortlisted for interviews, the panelists were shocked to realize that I had OCA. It took me several attempts to finally get a job".

This arises from people who do not wish any physical and/or social contact with albinos. If work environment for those who are employed is non- supportive, then it limits individuals with albinism from achieving their full potential. The study established that 11(50%) of the respondents were engaged in petty trading. Petty trading is usually done in the open space hence exposing persons with OCA to sunlight, predisposing them to skin cancer. Table4 below shows the distribution of respondents by sex, level of education and source of income.

Table 4: Distribution of Respondents by Sex, level of Education and Source of Income

Educational level	Formal		Petty trading		Cash transfers		Remittances		Total	%
	Male	Female	Male	Female	Male	Female	Male	Female		
Never attended school	0	0	0	0	0	0	0	1	1	5
Primary	0	0	0	1	0	1	0	0	2	9
Secondary	2	0	2	5	0	0	0	2	11	50
Tertiary	2	3	3	0	0	0	0	0	8	36
Total	4	3	5	6	0	1	0	3	22	100

N=22

The study also established that the major source of income for the respondents was petty trading, in which a total of 11 (50%) were engaged. The second major source of income was the formal sector with 7 (32%) respondents. Women with OCA face a daunting task in accessing education especially in Zimbabwe where the patriarchal system is still evident. This system favours males more than females when it comes to accessing education. This assertion is evident when most of the focus group discussion participant agree that when resources are not enough, the girl child with OCA chances of being send to school are slim They further stated that this is the case because they believe that girls will be married somewhere else and the onus will remain with the boy child to make sure that their lineage is perpetuated. The study established that 1 (5%)

woman with OCA never attended school and her major source of income was remittances. Upon

being probed on her educational status, one woman had this to say:

"I grew up in the rural areas before coming to town. My father disowned me and deserted us arguing that in their family no one has albinism. The ensuing challenges resulted in her dropping out of school".

4.2 Oculocutaneous Albinism and Self-esteem

Self-esteem is associated with having a positive attitude or acceptance of oneself. The ideal form

of self-esteem is derived from genuine respect shown to an individual by other people, because

of the inherent human worth and dignity (Lund, 2001). Social challenges like stigma and

discrimination, myths and misconceptions impact negatively on the self-esteem of persons with

oculocutaneous albinism. The study established that the mean self esteem score for the 30

respondents was 19; the median was 20 whilst the mode was 20. Self-esteem is an important

concept also noted and promoted by the Manicaland Albino Association. The mean score of 19

represent a normal range on the Rosenberg self esteem scale. It was worth noting that the mean

score for men was at 22 whilst that of women stands at 18. The lowest score (11) was recorded

by a female and the highest score (28) was recorded by a male respondent. Nevertheless, the high

self-esteem of many of the participants contradicted Gaigher et al's (2002) findings of low self-

esteem of all the learners with oculocutaneous albinism in a special school.

The figure 3 below presents the self esteem scores from the Rosenberg Self-esteem Scale

Figure 3: Rosenberg Self- esteem Scores

Rosenberg Self-esteem Scale Scores
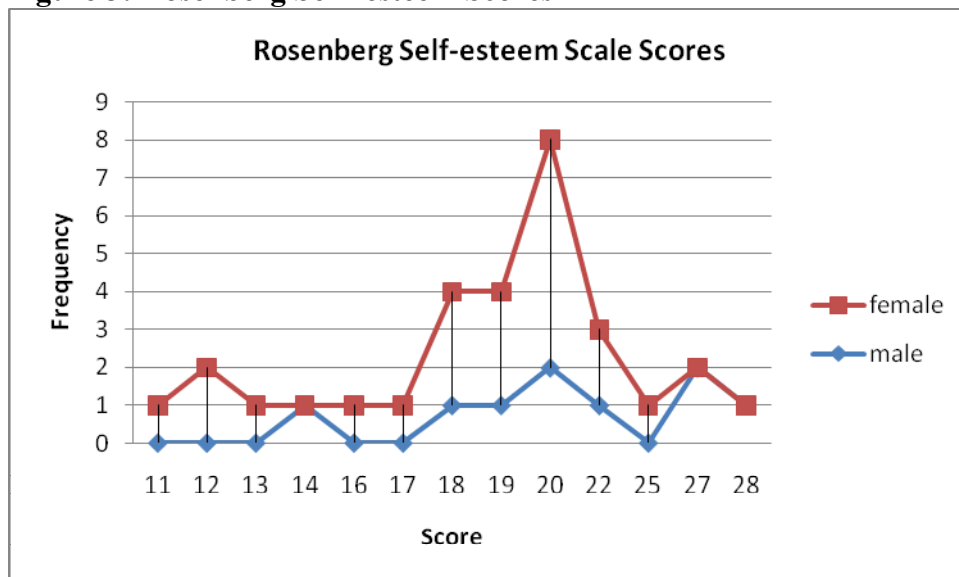
N=30

The study results as shown above are in tandem with what Kromberg and Jenkins (1984) established. Their study established that scores for teenagers with oculocutaneous albinism were high because they were contending with their personality. The inference of high scores by some of the respondents was as a result of self-worth which emanated from positive self-perception. This came out when one of the participants who is pursuing his education at tertiary level said:

"I am assertive and I believe in my potential. Iam a unique person and I will not allow anyone to taint my personality".

Ezeilo (1989) observed that such positive self image is crucial in fighting stigma and discrimination because the society will appreciate persons with OCA's dignity and worth hence will relate to them more positively than often the case.

On the other hand some respondents scored low on the scale. The study established that among those scoring low were divorced, single and separated persons with OCA. Separated respondents 6 (20%) indicated that they had been exposed to emotional abuse to the extent that they feel worthless and hopeless. As propounded in the social model of disability the society presents barriers in the form of negative attitudes that ultimately affect the quality of life for persons with OCA (Lang, 2001).

Closely linked with the self-esteem scores, the figure 4 below shows how often persons with OCA attend public events alone based on sex. The study established that 8 (27%) of the respondents occasionally attend public events alone, whilst 17 (57%) attend various public events more than once a month. One male (3%) indicated that he rarely attended public events alone. The study established that 4(13%) of the respondents attend public events more than once a week. The figure 4 below graph summarizes the above findings.

Figure 4: Distribution of Respondents by Attendance of Public Events.

N=30
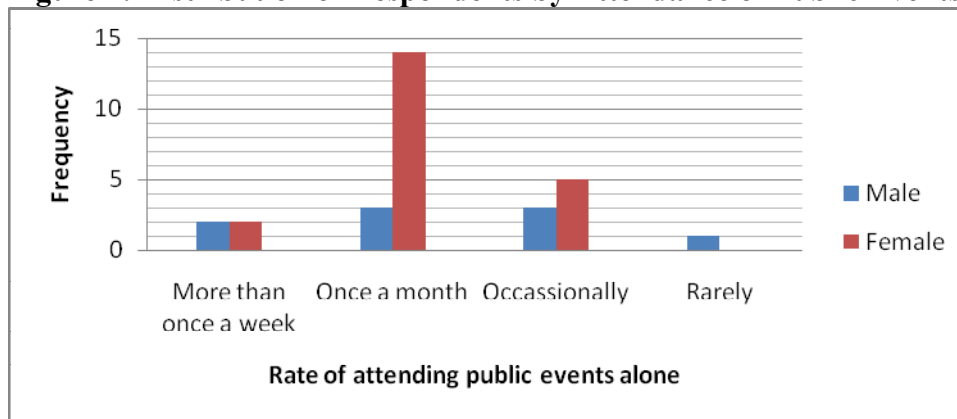
The study established that some persons with OCA have managed to be assertive and appreciated their self worth hence were able to participate fully in the society. On the other hand some persons with OCA have internalized the stigma and discrimination hence they are pessimistic about their life situations and are not outgoing.

4.3 Incidence of Abuse

From the focus group discussions it was noted that women with oculocutaneous albinism have a double tragedy, that of being women and at the same time having oculocutaneous albinism. The study established that 20 (67%) of the respondents were once abused in one way or the other whilst 10 (33%) indicated that they were not abused. The study established that (12) 40% of the women reported being emotionally abused, whilst (5) 17% of the men reported so. Also the study established that 2 women representing 7% were sexually abused and no males were sexually abused. Only 1 (3%) respondent reported that he was once physically abused. The study established that 20 (67%) of the respondents did report cases of abuse whilst 10 (33%) did not. The study established that those who did not report cases of abuse 6 (20%) were women and 4 (13%) were men. Quizzed on why they did not report the abuse most of the respondents said that they feel powerless in view of the largely abusive society. Ezeilo (1989:1130) and Lonsdale (1990:24) maintain that, as a result of curiosity, women with oculocutaneous albinism may be sexually exploited by members of the society rather than treated affectionately, and this in turn, may affect their quality of life and self-image. Table 5 below illustrates major type of abuse and sex of the participants.

Table 5: Distribution of Respondents by major type of Abuse.

Nature of Abuse	Male		Female			
	Yes	No	Yes	No	Total	%
Sexual	0	0	2	0	2	7
Emotional	5	4	12	6	27	90
Physical	0	0	1	0	1	3
Neglect	0	0	0	0	0	0
Total	5	4	15	6	30	100

N=30

The study established most of the victims of abuse experienced negative emotional reactions like fear, anger and depression. The above findings imply that persons with OCA are being demeaned by the society hence they are blatantly abused. Through socialization the society internalizes that persons with OCA are not important and are subjected to name calling, physical abuse and sexual abuse.

4.4 Knowledge of OCA by Respondents

Correct information is a critical tool to fight stigma and discrimination. The study established that 25 (83%) of respondents managed to correctly explain the cause of OCA. The research also established that 2(7%) respondents attributed OCA to witchcraft and 1(3%) respondent indicated that OCA is a result of a curse. Witchcraft was also highlighted by Lund and Gaigher (2002) when their study revealed that witchcraft was also being attributed to cases of OCA.The study

also established 2 (7%) respondents indicated that they did not know the etiology of OCA.
Figure 5 below shows the causes of OCA.

Figure 5: Causes of OCA

N=30
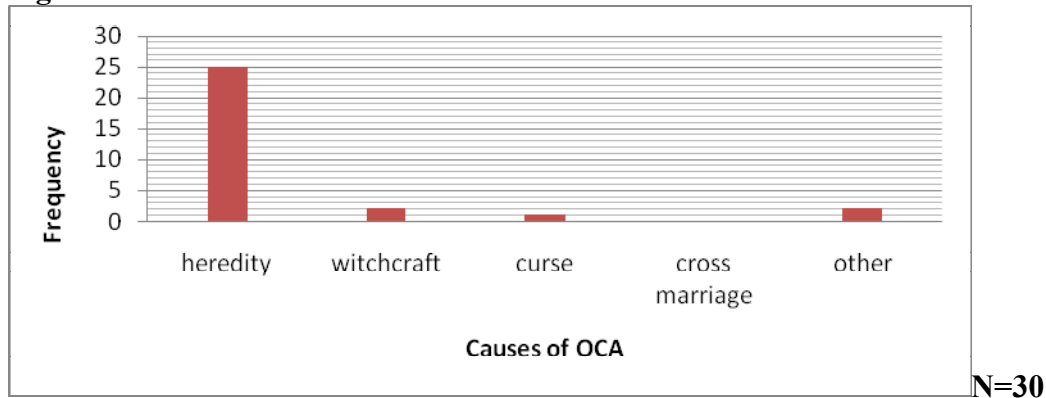
Such lack of information as shown above is not good for the fight against the social challenges like teasing and name calling faced by persons with OCA. One of the key informants highlighted that the local media was not doing much in disseminating information on OCA.The media was not forth coming in publishing articles related to OCA, claiming that it *'is not news worth'*. Even if they are invited to cover events in which persons with OCA are participating they give all kinds of excuses. Lack of funds to carry out awareness campaigns is also contributing to lack of information in the society.

4.5 OCA as a Disability

From the focus group discussions 95% pointed out that oculocutaneous albinism results in impaired vision hence it is classified as a disability. Only 5% were not sure why it is classified as a disability. This was a positive trend for the understanding of the condition hence crucial in the building of the self esteem of persons with oculocutaneous albinism.

Another significant finding that emerged was the participants' interpretation of oculocutaneous albinism as a disability. Various contradicting interpretations emerged, which also had an impact in terms of how society perceived a disability. It did seem that the interpretation was mostly influenced by the participants' personal experience. The respondents who supported the idea that oculocutaneous albinism is a disability shared their experience as follows:

"...OCA entails that we have visual impairment, which qualifies us to be classified as persons with disabilities. Also our physical experience exposes us to stigma and discrimination".

Some participants strongly felt that oculocutaneous albinism was not a disability, as one of them remarked:

"...no personally I do not think OCA is a disability, I disagree with that. I can undertake any activity just like anyone".

One of the key informants from the study indicated that some politicians query the classification of OCA as a disability. The key informant highlighted that a Member of Parliament queried the attendance of persons with albinism in a workshop for the disabled. The key informant went on to point out that government's commitment to alleviate social challenges faced by persons with OCA is questionable as there are no official statistics on the number of persons with OCA or OA in Zimbabwe and there are no policies and legislation that clearly spell out albinism as a disability. The government through its various departments present themselves as barriers to the fight against stigma and discrimination. The legislative structures are taking long to amend the Disability Act so that persons with OCA should have a legal recognition. This perpetuates the ambiguity of the condition hence the society will continue stigmatizing and discriminating them (Goffman, 1990).

4.6 Respondents Experience of the External Environment

The study established that the external environment has a bearing on the respondents' social experiences that ultimately affect their levels of self-esteem. George (2002) indicated that the external environment exists outside the person with oculocutaneous albinism, and is made up of all interactive influences that are outside the boundaries of the person. The family set up, the society, friends and the school constitute this external environment.

4.6.1 Family Attitudes Towards OCA

The family is regarded as the primary system (environment) for rearing a child, and that role is regarded as a right and not a privilege. It is critical that the family members have accurate information about albinism so as to fully comprehend OCA. Siblings need to appreciate why their brother or sister looks different and why they seem to be getting so much attention. The family is a profound force in assisting a child to understand and accept his or her self. From the study it was established that persons with oculocutaneous albinism are well accepted within their families as substantiated by the following excerpts:

"...l do not have challenges at home since my family really loves and appreciates me"

"...kumba hakuna matambudziko". (At home there are no challenges).

The study established that most of the focus group discussion participants indicated that they feel comfortable in their families. They reported that their immediate family members accept their condition and love them unconditionally. Within the family environment the study established that a child with oculocutaneous albinism was admired by other siblings. One respondent had this to say:

"Though my child has albinism, as a family we have accepted him just like any of the children"

The above findings concur with Gaigher et al (2002:9) finding that almost all the respondents in their study reported that their families treated them just like the rest of the family, regardless of their poor eyesight and skin challenges. Gaigher et al (2002) emphasised the critical role played by the family environment, when they said that lack of family support for a child with oculocutaneous albinism increases chances of later succumbing to society's negative attitudes and stereotyping.

The study also established that at times the family in its endeavor to accommodate a sibling with OCA becomes over protective. The research found that one respondent in the focus group discussion raised a concern about his parents who appear to be more concerned and overprotective as compared to other siblings. This was attested by the following response:

"...dzimwe nguva mhamha vanozonyanya, vanoda kuita make sure kuti ndiri kufara here".
(Sometimes my mother takes it to the extreme to ensure that I am happy).

King (2005) asserted that in an attempt to suppress feelings of personal guilt and external blame, many parents become overprotective of their child. On the other hand King (2005) argued that over protectiveness, fueled by pity and guilt may be not desirable when bringing up a child with OCA.

Though the family offers more psychosocial assistance to a child with OCA, it is not always the case. This came out from one of the key informant who alluded that there was a case of a child

with OCA in Nyanga rural who have been kept indoors for two years. The parents were afraid of the hostile society attitudes.

4.6.2 Perceived Attitudes of the Community Members

The study established that teasing and name calling was a challenge faced by persons with OCA emanating from the society. According to Hosking (2008) language is a powerful tool that is used in forming thoughts and reality. Teasing and name-calling are ways in which language can be dehumanizing. The word *'albino'* is widely used in several languages and it is borrowed from the Latin word *'albus'* meaning *'white'* (Hosking, 2008). The study established that 100% of the respondents were not comfortable with the term *'albino'*. The respondents argued that the word *'albino'* is used nastily. They felt that it is dehumanizing and demeaning to refer to a person in terms of a condition. Although slightly cumbersome, the terms *'person with albinism'* and *'people with albinism'* put the person first and the condition second. One respondent from the focus group discussion with persons with oculocutaneous albinism said:

"vanhu vakandiona ndichifamba vanobvunza vachiti musope kana kuti mualbino uyo ndiyani, asi nguva imwe cheteyo vakaona munhu asina condition yandinayo vanobvunza vachiti munhu uyo ndiyana.Zvinoreva here kuti handisiwo munhu"? Translated to English as *"if people see me they say who is that albino or 'musope', but at the same time if they see someone without the condition they will say who is that person? Does this mean that iam not a person"?*

The study also established that name calling and teasing was mainly done by children, though some adults were also found wanting. All respondents pointed out that lack of information coupled with mischief is the major cause of this scenario. This finding supports what NOAH (2005) established, that children are apprehensive when they see people who are different from

them for the first time. Failure to articulate their apprehension and questions constructively, results in name calling.

The study also established that some of the dehumanizing and demeaning terms include, *'murungudunhu' (fake white person), 'vakamenywa' (your skin is peeled), and 'vakafanana nenguruve '(you are light skinned like a pig)'*.

One of the key informants from the study commented that:

"Most of these words are used to depict negative attributes, which consistently influences society's negative attitudes towards people with OCA".

This finding concurs with the idealistic model of disability as propounded by Gleeson (1999).Gleeson (1999) stated that the idealistic model often cited in the field of social psychology and disability studies views persons with disability as constructed in the negative attitudes of society towards the impaired body. From this perspective, disability is understood as a negative trait that emerges from the stigmatizing interaction of members of society (Oliver, 1990). In other words, persons with OCA are disabled due to the interpretation and attitudes of the society towards them.

Due to lack of knowledge on oculocutaneous albinism by the society, most participants in the FGD with persons with OCA indicated that people curiously stare at them and were not comfortable with it. The respondents also highlighted that children come close and stare whilst adults usually steal glances at them. One key informant attributes this reaction to fear and inadequate understanding of the condition by some community members. Goffman (1990) is of

the idea that OCA is shrouded in ambiguity and to reduce this, society coin various names to refer to persons with OCA so as to make a meaning to this 'unusual' person in their midst.

Hosking (2008:14) points out that in spite of a persons' cultural background, people with disabilities are viewed as *"deficient, pitiable, wicked or malign, dangerous or valueless"*. Basing their argument on Hosking (2008), respondents from the focus group discussions pointed out that this has given the society the opportunity to look down upon persons with OCA. In response to these detrimental attitudes, one respondent said that:

"*We will continue rejecting devaluation by ignoring negative comments and not taking them to heart. Name-calling emanates from lack of information and incapacity to articulate questions constructively therefore it is the responsibility of every person to spread the accurate information on oculocutaneous albinism*".

This remark is in tandem with Rosenberg (1965) findings that individuals possess an ability to protect their self-esteem by rejecting the right of others to judge them. He further states that these defenses enable people to maintain their sense of worthy, ability, and power. When asked if society negative attitudes are a great challenge among persons with OCA. Tables 6 below show responses and frequency of the respondents.

Table 6: Negative Attitudes by the Society as a Challenge faced by Persons with OCA.

Sex	Strongly Agree	Agree	Not Sure	Disagree	Strongly Disagree	Total	%
Female	3	17	0	1	0	21	70
Male	1	6	0	2	0	9	30
Total	4	23	0	3	0	30	100

N=30

The table above indicates that 27 (90%) of the respondents confirm that indeed, negative society attitudes are a big challenge they are facing whilst 3 (10%) disagreed with it.

One of the key informants stated that some people are not comfortable in sharing seats in public transport and some especially in rural areas spit on the ground when they see a person with OCA. This concurs with what Goffman (1990) and Douglas (1966) established, that OCA is viewed as a contagious condition hence people try by all means to avoid them in public places or sharing items like plates and utensils. Goffman (1990) and Douglas (1966) also pointed out that as a counter measure to avoid 'catching' the condition or pass it to their unborn child pregnant women spit on the ground upon seeing someone with OCA and this perpetuates the social isolation of persons with OCA.

Despite the presence of perceived negative attitudes, some respondents reported that they are respected by some members of their communities. The study result contradicts with a previous report based on Zimbabwean sampling (Machipisa, 2002). In the report, it was indicated that people with oculocutaneous albinism were always shunned and treated as second-class citizens. One respondent was referred to as *'mayor'* by his colleagues and was comfortable with it. This was in apparent reference to the former mayor of Mutare town who was a white man. He claimed that though he was a grounds man, almost everyone knew him including the management and he was visibly proud of it.

Respect towards individuals with oculocutaneous albinism could be also emanating from the Shona belief that if one is heartless to someone with the condition, he/she will later bear such

child (Lund, 1997).This is supported when one participant from the focus group discussion with care facilitators said;

"...seka urema wafa". (Do not laugh at disability, you may also have disabilities).

4.6.3 Sense of Belonging

The study established that 4 (13%) (refer to figure 3) of the respondents scored below the acceptable score of 15 on the self esteem scale, the need for a sense of belonging need to be impacted among persons with OCA. From the focus group discussion with persons with OCA and care facilitators it was established the study respondents in one way or the other experienced social isolation in their lives. This was evident when one participant of the focus group discussions said:

"...since my husband deserted me, I feel lonely with no one to share my intimate thoughts".

Jordaan and Jordaan (1998) pointed out that social isolation is a part of loneliness and this loneliness is due to lack of friends that result in lack of a close and intimate relationship**.**

Some of the respondents indicated that change of environment triggers social and emotional loneliness as pointed out by one respondent:

"...l am more comfortable to interact with persons whom l already know, but if I travel to a new area I take some time before l establish contacts and friendship in that area".

4.6.4 Perceived Attitudes of Peers

The care and support from friends is critical in enhancing the respondents self esteem as shown by the following remark from the respondents:

"When I am with my friends I feel great and I have peace of mind".

Most of the participants in the focus group discussion with persons with OCA reported that they feel accepted by most of their peers of both sexes. These findings from the study are in contrary to findings by Lund (2001), where persons with OCA were avoided by their peers who refused to sit, eat, or play with them.

In concurrence with what Kromberg, Zwane and Jenkins (1987) established, one can say that cases of contradictions of findings point to the fact that negative attitudes directed to persons with OCA are changing from ignorance and superstition to understanding and acceptance.

4.6.5 The School Environment and OCA

The study established that the school or educational institutions played a fundamental role in the respondents' level of self esteem. The type of friends and staff at school either facilitated a sense of belonging or worsened the social isolation. This was proved when the study established that some teachers did not understand the participants' plight, especially visual challenges. The findings revealed that the negative attitude of some of the teachers affected the participants' self-esteem:

"I remember the first week at school was not good for me. My teacher always frowned and swore at me and made me sit at the back of the classroom though I could not see clearly until I had to tell my mother that I am no longer interested in attending school because sometimes I cry. That was when my mother visited the school to seek explanation from the headmaster on why the teacher was behaving that way and this really helped because the teacher changed her behaviour towards me after the meeting".

The above excerpt confirms the tenets of the social model, when it states that persons with disabilities major challenge are the unreceptive institutions and attitudes of the people (Oliver 1990).

However, it is worth noting that some teachers and school heads did understand the participants' plight. The study also established that participants were grateful to the Schools Psychological Services Department in the Ministry of Education Sports and Culture that have also taken the initiative to orient staff members about OCA. The efforts of the Schools Psychological Services Department were really praised by one of the key informants who said:

"...the Department is working hard to ensure that persons with disabilities, including albinism are well accepted and understood by both teachers and pupils. They do this through awareness campaigns on disability issues. Their efforts might tempt one to suggest that this marks a change towards a successful integration of persons with OCA in the educational system".

4.7 Feeling of Being Stigmatised and Discriminated

Goffman (1990) asserted that stigma is a social process of devaluing people or groups based on a real or supposed difference and it has resulted in persons with OCA being unjustifiably rendered shameful, excluded and discriminated against in society. From the participants' remarks, they felt that they were being socially stigmatised on the basis of their physical appearance. One respondent indicated that children shout at her saying, *'wakamenywa' meaning your skin is peeled* .This scenario concurs with what Lund (2005) pointed out, he asserts that persons with OCA lack of pigmentation exposes them to stigma. Gaigher et al (2002) also buttress the above assertion when he argued that stigma is associated with deviation from what the society normally expects. Lack of pigmentation has attracted stigma for persons with OCA because society perceive them as a deviation from what is usually expected (Gaigher et al, 2002). The above point was echoed by the participants from the focus group discussion when one of them said:

"I think our physical experience exposes us to stigma and discrimination because the society perceives us as abnormal beings and this has been a barrier to full social integration and has disrupted social relationships".

The study also established that cultural beliefs and superstitions on oculocutaneous albinism were triggering stigma and discrimination. These unempirical perceptions of oculocutaneous albinism had a negative bearing on the respondent social life, as some of the focus group discussion participants indicated that they were not comfortable in attending public functions alone for fear of stigma. One misconception coming from the focus group discussion was that some people in the society were attributing OCA to some form of punishment from the ancestral spirits. This is exemplified when one participant said:

"Vanhu vanonditi mufana vakazvarwa midzimu yakatsamwa".Which is loosely translated to "people say that I was born when my ancestors were angry".

One of the key informants further elaborated on the effects of stigma and discrimination on the social life of persons with OCA, when he said:

"It is evident around town that stigma results in stereotyping, embarrassment, anger, and avoidant behaviors by some persons with oculocutaneous albinism".

Study findings also concur with Small (1998) who established that some parents and persons with OCA internalize negative attitudes from the society leading to self blame as asserted by one key informant who said:

"Some of the persons with oculocutaneous albinism think that it is normal for the society to express negative reactions towards them and to avoid bothering it is wise to shun situations that attract stigma. They would have lost hope in the system to liberate them".

The study also concurs with what Machipisa (2002) established, that due to stigma and discrimination persons with OCA are treated with contempt and this leads to social exclusion, bullying, aggression, ridicule and devaluation of the self-worth of the person. Therefore, discrimination creates a vicious circle of poverty and social isolation for persons with OCA. Table 7 below shows the responses of the respondents when they were asked if avoiding public events was a way of avoiding stigma and discrimination.

Table 7: Avoiding Public Events as a way of Avoiding Stigma and Discrimination.

	strongly Agree		Agree		Not Sure		Disagree		Strongly disagree			
Age Range	Male	Female	Male	Female	Male	Female	Male	Female	Male	Female	Frequency	%
0-18	0	0	0	0	0	0	1	5	0	0	6	20
19-40	0	1	1	9	0	0	5	3	1	1	21	70
41-60	0	0	0	0	1	1	0	1	0	0	3	10
above 60	0	0	0	0	0	0	0	0	0	0	0	0
Total	0	1	1	9	1	1	6	9	1	1	30	100

N=30

The above table indicated that 1 (3%) of the respondents strongly agreed with the statement, 10 (33%) agreed with the statement, 2 (7%) were not sure, 15(50%) disagreed whilst 2 (7%) strongly disagreed with the statement.

4.8. The Emotional Component of Oculocutaneous Albinism

Waugh (2005) asserted that external influences of society attract an emotional response by persons with OCA so as to develop a personality and cope with the condition. The expression of emotions reduces stress and depression whilst suppressing it causes otherwise. Machipisa (2002) argued that the emotional response to OCA occurs throughout life due to embedded challenges and frustrations presented by the condition. The following were some emotions that persons with OCA highlighted in the study.

4.8.1. Anger

Machipisa (2002) stated that persons with OCA may experience anger at themselves or others for perceived injustices or losses associated with their condition which they may believe was caused by negligence or was avoidable. If persons with OCA identify themselves as victims their anger may be directed toward the persons or circumstances they blame for the condition or situation (Machipisa, 2012). If they believe that their own actions were partly to blame for the disability, the anger may be directed inward. The above assertions were established by the study when one participant said:

"...sometimes I feel angry and I cry when iam teased or subjected to name calling. Sometimes I am angry with the government for failing to fully protect us from abuse".

Brown and Mankowski (1993) stated that anger can be the result of frustration. Anger turned inward leads to depression. Brown and Mankowski (1993) stated that depression, with attendant feelings of inadequacy, helplessness and hopelessness, leads to emotional withdrawal.

4.8.2 Depression

The study established that persons with OCA sometimes experience depression due to loneliness. This was evidenced when one of the participants said:

"...sometimes I feel I do not want to interact with the outside world, but I end up thinking too much and I do not want to talk to anyone".

Machipisa (2002) argued that with the realization of the reality, seriousness, and implications of OCA individuals may experience feelings of depression, helplessness and hopelessness, apathy, and/or feelings of dejection and discouragement. From the previous discussions the study

established that persons with OCA experience episodes of depression which results in withdrawal from any activity and emotional bursts.

4.8.3. Guilt

The study established that persons with OCA sometimes feel guilty and this has led to social withdrawal. The findings pointed out that persons with OCA end up criticizing themselves upon being blamed by others. This scenario was evidenced when 1 female participant with OCA said:

"...my husband and the society blamed me when I gave birth to a child with OC. now my child is being emotionally abused at school and everyone is pointing a finger at me as the source of all these problems. Sometimes I question myself why I decided to have a child. I think I should have not started a family".

The above excerpt concurs with Lund (2001) when he said that persons with OCA or family members may harbor feelings of guilt if they think they contributed to, or in some way caused, the condition (Lund, 2001). Ezeilo (1989) further highlighted that in other instances persons with OCA may experience guilt because they believe their condition is a burden to the family. Self-blame or blame ascribed by others is harmful not only to the individual's self-esteem, but also to rehabilitative efforts as a whole (Fishbein and Ajzen, 1975).

4.9 Coping Mechanisms

The study established that persons with OCA sought social support from organisations so as to reduce the impact of stigma and discrimination .These organisations include Youth Alive, Manicaland Albino Association and Mercy Corps. The church and the government are also chipping in to alleviate the challenges being faced by persons with OCA.The table below

establishes that the church has been cited as the major provider of assistance with 15 (50%) receiving some form of assistance which include blankets and counseling. Prayer and meditation was also highlighted by the participants as a way of managing depression. The study established that NGOs like Mercy Corps has partnered with the Manicaland Albino Association in providing basic needs for the members in the form of small grants that are used to purchase protective hats and blankets. The Manicaland Albino Association has also sourced skin lotions for use by persons with OCA. The study established that 11(37%) of the respondents were receiving help from NGOs and 4 (13%) were receiving government support. Table 8 below shows the source of assistance and type of assistance provided to the respondents.

Table 8: Sources of Assistance and type of Assistance Provided.

	counseling	Cash	material	other	total frequency	Total %
Government	0	2	2	0	4	13
Church	2	4	9	0	15	50
Individual	0	0	0	0	0	0
NGO	6	0	5	0	11	37
Other	0	0	0	0	0	0
Total	8	6	16	0	30	100

N=30

The study also established that the church plays a critical role in offering spiritual counseling to persons with oculocutaneous albinism and their families. The above-findings concur with what Marx (1884) and Durkhaim(1915) postitulates about the roles and function of religion. Religion is viewed as a unifier of various commnunities and a platform where stigma and discrimination can be fought.

From the focused group discussions most of the partipants indicated that care facilitators within their locations were helping by informing community members on OCA.The partipants indicated that information on the causes of OCA is shared in various fora. The participants also pointed out that care facilitators were linking them with service providers in Mutare and beyond, for example where to get lotions. Reporting cases of abuse was also highlighted as a coping strategy. This was the case for a woman with OCA who was sexually abused and proceeded to make a police report and the perpetrator was convicted and sentenced. Most of the participants in the FGD agree that it is crucial to remove perpetrators of sexual abuse from the community so that they could feel free to move about.Cases of teasing and bulliying were reported to parents, teachers and church leaders who inturn provide counselling to the victims.

Crying was also mentioned as a coping mechanism from the FGD participation. They argue that when one cries, emotions arereleased and one will feel much better. Some of the focus group discussion participants indicated that they cry when they have been emotionally abused by husbands or other relatives.

Defensive coping strategies like avoiding public places in an effort to evade stigmatisation was also highlighted by the participants.

The study concurs with Miller and Major (2000) assertion that coping mechanisms can be broadly categorised into two groups, engagement and disengagement. By seeking social support persons with OCA will be trying to gain control over a given psychosocial challenge (engagement). On the other hand disengagement coping strategies employed by persons with OCA include physical and social withdrawal (Miller and Major, 2000).

4.10 Conclusion

The chapter has discussed the psychosocial implications of albinism and coping strategies employed by persons with OCA in face of challenges. These findings were discussed within the confines of the aim, objectives of the study and were grounded on the social model of disability as outlined in chapters 2 and 3. The study established that stigma and discrimination was negatively affecting the self esteem of persons with OCA.at also established that due to stigma and discrimination emotions like anger were triggered. Emotional coping strategies like crying was employed by persons with OCA.The study established that social support through individuals and organisations was also employed as a coping strategy.

CHAPTER 5

5.0 SUMMARY, CONCLUSIONS AND RECOMMENDATIONS.

5.0.1Introduction

The chapter outlines the summary and conclusions of the study taking into consideration the findings presented in chapter 4.The study will then go on to recommend action points for the mitigation of the psychosocial challenges faced by persons with OCA.

5.1 Summary

The disability aspects of OCA are defined by the reduced visual acute of individuals with the condition. The physical appearance of persons with OCA has exposed them to stigma and discrimination resulting in psychosocial challenges as discussed in chapter 4. The study concurs with Mtetwa (2012) when he asserted that impairment is viewed as normal by the social model of disability, but what give rise to challenges they face is a plethora of stigma and discriminations manifested in cultural beliefs, misconceptions and negative social attitudes.

The study established that the mean age of the respondents was 33 years and the majority of the respondents 20 (67%) of the respondents were in the range of 19 to 40 years. The finding buttresses Makumbe' assertion in the Newsday paper that persons with OCA have been socially excluded to the extent that most of them die at a young age due to poor management of the condition especially cancer. (www.newsday.co.zw).

The study established that members of the Manicaland Albino Association in Mutare urban have been exposed to various forms of abuse especially emotional abuse which have a toll on their

well being. Teasing and name calling are some of the psychosocial challenges that are being faced by the members of Manicaland Albino Association in Mutare urban. Some respondents indicated that due to stigma and discrimination they end up experiencing depression. This has resulted in some persons with OCA scoring low on Rosenberg self esteem scale. Some of the respondents indicated that they feel helpless and hopeless in the face of stigma and discrimination. The study established that there is a relentless attack on the dignity and self worth of persons with OCA that has led to the internalization of oppression. The study established that some persons with OCA were not comfortable with walking alone in public for fear of stigmatization and discrimination. This situation might have contributed to the low score of 11 on the Rosenberg self esteem.

The highest score on Rosenberg self esteem scale was 28 and this points to the fact that some persons with OCA are managing to cope with their condition. It is also worth to note that name calling does not always portray a negative image. One of the respondents attributed his popularity at workplace to name calling and he clearly indicated that he felt great about it.

Marriage is a critical social institution that has some positive attributes. The study established that not all persons with OCA are enjoying the benefits accrued through marriage. Of the 30 participants, 13 (43%) were single, 5 (17%) never married, 5 (17%) were married and 6 (20%) separated with their spouses. The study established that most persons with OCA were in separation or divorce as a result of husbands deserting and disowning a child born with OCA. Some indicated that some spouses just wanted to have a *'feel'* of a woman with OCA and immediately dump her. Others have opted to stay single because they do not trust a marriage

union especially with someone without OCA. Those who married women with OCA just want to experiment and desert them. This scenario is evidenced when the study established that 80% of the respondents are from female headed households whilst 20% come from male headed households.

The study established that 8 (27%) respondents reached tertiary education, 11 (38%) indicated that they have reached secondary level whilst 1 (3%) indicated that he never attended school. The study found that factors that have militated access to education by person with OCA include marital problems and the negative attitudes of some teachers. The study also established that few persons with OCA are in formal employment because potential employers discriminate against them.

The study established that there is a lack of information on the etiology of OCA as indicated by the responses of the respondents. Most of the respondents highlighted that OCA is caused by heredity and some pointed to witchcraft and a curse whilst, others were not sure. The study also established that 5% of the respondents were not sure if their condition can be classified as a disability. This ambiguity in the etiology of OCA has further perpetuated the social exclusion of persons with OCA.

The family plays a very critical role in the lives of persons with OCA as most of the respondents indicated that they feel well accepted by the family. This is in contrast to their experience in the society where they are stigmatised and discriminated. There were also cases of overprotection of persons with OCA from family members.

Religion was critical as a coping strategy in the lives of persons with OCA as shown by their affiliation to various denominations. The church was offering help to enable persons with OCA to cope with material and emotional needs. Prayer and meditation was mentioned as a way of managing depression.

As a coping strategy emotional regulation and release was employed by the members of the Manicaland Albino Association in Mutare urban. Social support was also being provided by the care facilitators where they conduct home visits to provide counseling and linking members with resource systems.

5.2. Conclusions

The study sought to investigate the psychosocial implications of OCA among the members of the Manicaland Albino Association in Mutare urban. The study established that persons with OCA suffer from incidences of stigma and discrimination that prevents them from fully participating in mainstream society activities. Institutions like the government and its arms, the private sector and social institutions at some point are not receptive to the needs of persons with OCA hence they become barriers to the fulfillment of their rights. Psychosocial effects of albinism manifest themselves on work, marriage, school and personal relationships.

The biological characteristics of persons with oculocutaneous albinism have been misconceived and have a bearing on their psychosocial lives. Features like the inability to produce melanin resulting in fair skin and hair have exposed persons with the condition to stigma and discrimination. Name calling, teasing, building relationships and marriage issues are some of the

challenges that were being faced by the respondents. These social challenges ultimately have a bearing on the levels of self esteem for the respondents.

The quality of life for persons with OCA has been negatively affected by the lack of community consciousness, negative cultural beliefs and myths within the society. A discriminatory society has resulted in an economically disadvantaged group of individuals that is engulfed in a vicious cycle of isolation and poverty. The family plays a critical role in the lives of persons with OCA as all the respondents indicated that they feel well accepted. Some sections of the community still expose persons with OCA to stigma and discrimination and this has led to low scores of self-esteem among persons with the condition.

To conclude, the study established that members of the Manicaland Albino Association in Mutare urban face psychosocial challenges associated with misconstrued etiology of the condition. This has culminated in low self esteem levels among them. Women with the condition face a double tragedy in a patriarchal society and tend to suffer more as compared to their male counterparts. Negative cultural beliefs and the lack of knowledge on the genetic inheritance of albinism make it difficult for persons with albinism to start and sustain relationships. In the face of the presented psychosocial challenges persons with OCA have employed coping strategies like seeking social support and releasing emotions. The social model of disability applied to persons with OCA situation has been useful in explaining the psychosocial implications of OCA.

5.3 RECOMMENDATIONS

Having established the psychosocial implications of OCA among members of the Manicaland Albino Association in Mutare urban the study will come up with recommendations that seek to find solutions to some of the psychosocial challenges facing persons with OCA. From the findings it is recommended that:

- The government, the private sector, non-governmental organisations, the church and other partners should support awareness campaigns on oculocutaneous albinism. This would enable the society to have correct information on the condition that would reduce incidences of stigma and discrimination.

- Sensitization programmes around OCA should be intensified in schools to create awareness of the conditions to both pupils and teachers so that they can fully accept and accommodate pupils with OCA.

- Local leadership and spiritual leaders should have correct information on OCA so that they become role models. Due to their influence in society they have the potential to fight stigma and discrimination perpetuated by negative cultural beliefs.

- Men should be actively involved in the fight against social stigmatization and discrimination of persons with OCA. Men are found to desert their spouses upon the birth of a child with OCA.

- Organisations that promote the rights and welfare of persons with OCA should use existing opportunities to educate the society on albinism, for example asking for some time after church services to impart knowledge. In face of few resources this is a strategy that will ensure that knowledge is disseminated across the community.

- The government should review the current Disability Act to include albinism as a disability so as to have legal recognition. The government should provide free lotions to persons with OCA, and these should be available in every health care center to improve of accessibility by persons with OCA.

- Training is also vital for the reduction of stigma and discrimination. Health care providers, community workers, family members as well as persons with OCA need to be trained on the etiology of OCA so as to influence positively society perception on the condition. The print and electronic media must also be utilized to reach more people in addressing this issue.

- More researches must also be conducted to study the impact of ethnicity, religion, culture, sex etc on stigma and discrimination. New findings must be explored and implemented to help reduce the spread of stigma and discrimination.

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List of Appendices

Appendix 1

Consent Form

Statement of Consent

My name is Fungayi Mutasa and i am a student with the University of Zimbabwe; School of Social Work .Iam conducting a research on the challenges being faced by persons with oculocutaneous albinism in Mutare urban. It is my hope that the results are to inform policy formulations and programme designs by various actors.

Feel free to ask clarity on the questions and if you feel you can no longer continue with the interview you are free to withdraw at any stage. Pseudo names are to be used in the report to be generated.

The information you reveal tome would be anonymous, confidential and would not be attributed to you. If you are in agreement, then you could give me confirmation in principle and we could proceed.

Yes or No

Thank you

Appendix 2: Research Instruments.

2 a. Interview Schedule

QUESTIONNAIRE ON THE SOCIAL CHALLENGES FACED BY PERSONS WITH OCA IN MUTARE URBAN.

Questionnaire ID

My name is Fungayi Mutasa .Iam a final year student studying towards a Master of Social Work degree with the University of Zimbabwe School of Social Work. Iam conducting interviews with persons with oculocutaneous albinism to understand the psychosocial implications of the condition. The information obtained will culminate into a dissertation that can be used for planning and programming purposes.

No names or house numbers are to be recorded.

Are you willing to be interviewed?   Yes   No

Interview details

Date…………………………………………………….

District: Mutare

Location: Mutare Urban

Section A: Demographic characteristics.

Q Number	Questions and filters	Coding categories	Code
Q1	Sex of household head	1=male 2=female	
Q2	Sex of respondent	1=male 2=female	
Q3	Marital status of the respondent	1=single 2=never married 3=married 4=divorced 5=separated 6=widowed	
Q4	Denomination of the respondent	1=Protestant 2=Pentecostal 3=Apostolic sect 4=African Traditional 5=others (specify)	
Q5	Age of respondent	1=0 to 18 years 2=19 to 40 years 3=41 to 60 years 4= above 60 years	
Q6	Education level of respondent	1=never attended school 2=primary level 3=secondary level 4=tertiary level	

Section B: Household economy and access to goods and services

Q7	What is your major source of income?	1=formal employment 2=petty trading 3=cash transfers 4=farming 5=remittances 6=casual labour 7=other (specify)…………………………….	
Q8	Nature of employment	1=formal 2=informal 3=N/A	
Q9	If employed what are the challenges you are facing?		
Q10	In the previous year did you received any help	1=yes 2=no	
Q11	If yes, which organization(s)/ individuals assisted you?	1=government 2=church 3=individual 4=NGO	
Q12	Nature of support received	1=counseling 2=cash 3= material 4=Other (specify)	
Q13	Have you sought medical assistance in the past year to alleviate sunburn or other challenges	1=yes 2=no	
Q14	If no, why	1=health fees expensive 2=health staff unfriendly 3=not allowed to go outside home 4=never had any health problems.	

		5=Other (specify)	
Q15	Are you aware of any other organization that helps persons with oculocutaneous albinism	1=yes 2=no	
Q16	If yes name the organization and type of assistance offered.		
Q17	Are you comfortable in attending public events alone?	1-yes 2=no	
Q18	How often do you engage in social activities outside of your home e.g. visiting friends	1=more than once a week 2=once a month 3=occasionally 4=rarely	

Section C: Knowledge and Attitudes

Q19	Do you know what causes oculocutaneous albinism	1=yes 2=no	
Q20	If yes, specify	1=heredity 2= witchcraft 3=curse 4=cross marriages 5= Other(specify)	
Q21	Have you ever received any information on albinism	1=yes 2 =no	
Q22	Are you aware of any piece of legislation that promote the rights and wellbeing of persons with oculocutaneous albinism?	1=yes 2=no 3=not sure	
Q23	If yes, can you name it.		
Q24	How do you rate your degree of knowledge on oculocutaneous albinism	1=very good 2=good 3=acceptable 4=poor.	
Q25	What is your status in the family?	1=extra privileged 2=well accepted 3=tolerated 4=stigmatized	
Q26	What is your status in the community?	1=extra privileged 2=well accepted 3=tolerated 4=stigmatized	
Q27	Doctors and other medical	1=strongly agree 2=agree 3=not sure	

	professionals knows what is best for you	4=disagree 5=strongly disagree	
Q28	To avoid stigma and discrimination it is better to avoid public places	1=strongly agree 2=agree 3=not sure 4=disagree 5=strongly disagree	
Q29	The reason most persons with oculocutaneous albinism are unemployed is that they are not able to do the jobs that are available	1=strongly agree 2=agree 3=not sure 4=disagree 5=strongly disagree	
Q30	The biggest challenge faced by persons with oculocutaneous albinism is attitude of other people	1=strongly agree 2=agree 3=not sure 4=disagree 5=strongly disagree	
Q31	Are you subjected to name calling?	1=yes 2=no 3=not sure	
Q32	If yes to Q31 can you specify		
Q33	I would associate with persons with oculocutaneous albinism than with people without the condition	1=strongly agree 2=agree 3=not sure 4=disagree 5=strongly disagree	

Section D: Stigma and discrimination

Q34	Do you think you cause embarrassment burden to the family.	1=yes 2=no	
Q35	Have you been abused before	1=yes 2=no	
Q36	If yes. State nature of abuse.	1-sexualabuse 2=emotional abuse 3=physical abuse 4=neglect	
Q37	Did you report the abuse to anyone?	1=yes 2=no	
Q38	If yes, what action was taken		
Q39	If no give reasons		
Q40	Have you been subjected to name calling?	1=yes 2=no	
Q41	If yes specify		

Thank you

2 b. Focus Group Discussion with Persons with Oculocutaneous Albinism

1. Is albinism a disability? If yes or no explain.

2. Which types of albinism are you aware of? Give a brief explanation.

3. Do you feel you are receiving adequate assistance from the government, the family, the community, private organizations and NGOs?

4. Besides the Manicaland Albino Association are you aware of any other organization that specifically attend to your rights and needs.

Societal attitudes and self-esteem

5. Briefly describe the attitudes of community members towards you as persons with oculocutaneous albinism.

6. Briefly describe the attitudes of your peers towards you as persons with oculocutaneous albinism.

7. Briefly describe the attitudes of your family towards you as persons with oculocutaneous albinism.

8. At school what are challenges facing persons with OCA?

9. What can be done to improve the psychosocial life of persons with OCA?

2c: Focus Group Discussion with Care Facilitators

1. Is albinism a disability? If yes or no explain.

2. Which types of albinism are you aware of? Give a brief explanation.

3. In your view are persons with OCA facing stigma and discrimination. Explain n dive examples.

4. Besides the Manicaland Albino Association are you aware of any other organization that specifically attend to the rights persons with OCA.

Societal attitudes and self-esteem

5. Briefly describe the attitudes the community members towards persons with oculocutaneous albinism.

6. Are you comfortable working with persons with OCA.

7. Briefly describe the attitudes of your family towards you as a care facilitator working with persons with oculocutaneous albinism.

8. Are their incidences where persons with OCA are kept at home or subjected to ill treatment?

9. In your view what can be done to improve the social life of persons with OCA2.

2d: Key Informant Guide for the Manicaland Albino Association

1. What is the nature of support you provide to persons with albinism? (Explain).

2. How long has been your organization providing help to persons with albinism?

3. How many donors are funding your operations?

4. What is the nature of help did you receive from the government.

5. Is the support from government and donors enough? (Explain).

6. Do you hold awareness campaigns and what has been the coverage?

7. What has been the major psychosocial challenges being faced by persons with oculocutaneous albinism?

8. Do you know of any cases were persons with oculocutaneous albinism have been abused, neglected or killed for ritual purposes? Explain.

9. In your opinion what can be done to improve the social life of persons with albinism?

2e: Key Informant Guide for the Department of Social Services Head.

Knowledge

1. Is albinism a disability? If yes or no explain.

2. What causes albinism? Explain

3. Which types of albinism are you aware of? Give a brief explanation

4. Does your organization work with persons with albinism, if yes explain the nature of support, if no has been your organization been approached by persons with albinism for help.

5. If persons with albinism come seeking assistance where do you refer them to?

Societal attitudes and self-esteem

4. Briefly describe the attitudes of the community members towards persons with oculocutaneous albinism.

6. Are you comfortable with any of your close family members marrying a person with albinism? Explain.

7. What recommendations can be made to improve the quality of life of persons with OCA?

2d: Rosenberg's Self-Esteem Scale

Instructions:

Below is a list of statements dealing with your general feelings about yourself.

If you **strongly agree**, circle **SA.**

If you **agree** with the statement, circle **A.**

If you **disagree**, circle **D.**

If you **strongly disagree**, circle **SD.**

statement		Strongly Agree	Agree	Disagree	Strongly Disagree
1	I feel that I am a person of worth, at least on an equal plane with others.	SA	A	D	SD
2	I feel that I have a number of good qualities.	SA	A	D	SD
3	All in all, I am inclined to feel that I am a failure.	SA	A	D	SD
4	I am able to do things as well as most other people.	SA	A	D	SD
5	I feel I do not have	SA	A	D	SD

	much to be proud of.				
6	I take a positive attitude toward myself.	SA	A	D	SD
7	On the whole, I am satisfied with myself.	SA	A	D	SD
8	I wish I could have more respect for myself.	SA	A	D	SD
9	I certainly feel useless at times.	SA	A	D	SD
10	At times I think I am no good at all.	SA	A	D	SD

Your score on the Rosenberg self-esteem scale is: ☐.

Scores are calculated as follows:

- *For items 1, 2, 4, 6,* and *7:*

  Strongly agree = 3

  Agree = 2

  Disagree = 1

  Strongly disagree = 0

- *For items 3, 5, 8, 9,* and *10* (which are reversed in valence):

    Strongly agree = 0

    Agree = 1

    Disagree = 2

    Strongly disagree = 3

The scale ranges from 0-30. Scores between 15 and 25 are within normal range; scores below 15 suggest low self-esteem.

Thank you.