

CHAPTER ONE

INTRODUCTION

1.1. General Introduction

Albinism is a congenitally inherited hypomelanosis that may involve the normally pigmented structures of the body such as the eyes, skin, and hair. The condition is generally classified into ocular albinism (OA) and oculocutaneous albinism (OCA) types. When only the eyes are affected, the condition is called ocular albinism, whereas when both the eyes and the skin are affected, the condition is called oculocutaneous albinism (Oetting, Brillian & King, 1996). Oculocutaneous albinism (OCA) is a recessive genetic condition prevalent throughout sub-Saharan Africa. In indigenous Black populations, OCA subjects have sandy coloured hair, pale chalky white skin, often burned by the sun and blue to light brown eyes showing nystagmus (rapid eye movements), photophobia, lack of binocular vision and poor acuity (Gaigher, Lund & Makuya, 2002). This condition is more common amongst Black population than Whites. The prevalence is approximately 1 in 3900 in South African Black population compared with 1 in 15000 Whites, 1 in 9650 in Norway, 1 in 10,000 in Northern Ireland (Kromberg & Jenkins, 1982; Magnus, 1992; Sanders, 1938). Most people appear not to be enlightened with regard to albinism because it is a rare condition. On the other hand, people with this condition appear to see themselves as being trapped in a situation of not fully understanding whether they are a fit or a misfit in the society.

There seem to be various perceived societal attitudes towards people with the condition which vary from person to person at different stages of life. Children and teenagers with oculocutaneous albinism in the Black African communities appear to be facing challenges that result in a range of social, psychological, and educational problems (Gaigher, Lund & Makuya, 2002). According to Magnus (1992), the functioning of people with this condition often seem to be hindered by the behaviour of fellow citizens, because in most cases these individuals seem to be treated like outcasts and shunned or sometimes even murdered.

Children with this condition appear to be severely affected because they seem not to understand the difference between themselves and other individuals who are different from them. Because of this, they appear to be feeling isolated not only in physical appearance but also in conduct of everyday life, thus affecting their self-esteem (Lund, 2001).

Lund (2001) further states that children and teenagers with albinism also seem to continue to experience problems caused by their conditions both at school and home. Their physical condition seems to make their lives difficult because most of them are called names, ridiculed, beaten and humiliated publicly, and rejected by both teachers and other peers who are different from them. The beliefs of the society in general appear to be leading these minority groups to see themselves as a misfit or outcast, avoided by their peers who sometimes refuse to sit, eat, or play with them.

1.2. Statement of problem

The prevalence of oculocutaneous albinism continues to grow in the Black South African society, but not much has been researched about the psychological impact this condition might have on the people living with it. Since 1971, research on oculocutaneous albinism has been carried out in the Human Ecogenetics Unit of the Medical Research Council of South Africa. Investigations were aimed at determining the prevalence of this condition among South Africans, reason for high prevalence, together with their skin and visual problems (Kromberg, 1987). However, concern about their psychosocial well-being has not been sufficiently investigated. With limited information, the researcher found it appropriate to explore more about the self-esteem of teenagers with oculocutaneous albinism and the perceived societal attitudes towards them.

1.3. Aim of the study

The aim of this study is to explore the self-esteem of teenagers with oculocutaneous albinism and perceived societal attitudes towards them.

1.4. Objectives

The objectives formulated for the study are:

- (a) To explore the self-esteem of teenagers with oculocutaneous albinism.
- (b) To explore the perceived societal attitudes towards teenagers with oculocutaneous albinism.

1.5. Scope of the study

The researcher focused on areas around Capricorn District of the Polokwane Municipality, Limpopo Province, South Africa. The Municipality is divided into four clusters. Cluster A consists of Molepo, Maja, and Chuene. Cluster B consists of Mankweng and Sebayeng villages. Cluster C consists of Moletjie village whereas Cluster D consists of the Polokwane City and Seshego. The population in the Municipality is approximately 44,111 (Polokwane Municipality, 2003). Both regular and special schools within these areas were targeted for this study because participants basically consisted of the school-going age group.

1.6. Significance of the study

The study will be of great significance to the body of knowledge in the field of social sciences, specifically psychology as it explores the self-esteem of teenagers with oculocutaneous albinism and different societal attitudes towards the people with the condition. It will also be of great assistance to the Department of Education, especially on the development of policies protecting the rights of learners with oculocutaneous albinism and appropriate placement of these learners in schools. Above all, it will be of help in the enlightenment of South Africans with regard to albinism.

CHAPTER TWO

THEORETICAL PERSPECTIVES

2.1. Introduction

The operational definitions of concepts, the theoretical concepts on albinism and self-esteem are presented in this section.

2.2. Operational definition of concepts

a. Albinism

According to Oetting, Brilliant and King (1996), albinism is defined as a group of inherited anomalies of melanin synthesis. It is characterized by a congenital reduction or absence of melanin pigment in association with specific developmental changes in the visual pathway resulting from structural hypopigmentation.

b. Oculocutaneous albinism (OCA)

Oculocutaneous albinism (OCA) is a form of albinism in which the skin, hair, and the eyes lack pigmentation (Oetting, Brilliant & King, 1996).

c. Ocular albinism (OA)

Ocular albinism has the same changes in the eye and 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 effect in the colour of the skin and hair. The skin and hair of the individual may appear normal (Oetting, Brilliant & King, 1996).

d. Self-esteem

According to Hewitt (1991), self-esteem refers to the positive or negative sentiments that people attach to themselves as a result of their experiences in social life. It is a reflection of how one evaluates the self. It derives from individuals' thoughts and feelings with reference to themselves as objects. It is an attitude of approval or disapproval. It indicates the extent to which individuals believe to be capable, significant, successful, and worthy (Brinthaupt & Lipka, 1994; Rosenberg, 1965). However, self-esteem is perceived as multidimensional, multifactorial fluctuating attribute which while having a baseline, changes according to the roles and expectations of the self and others (Flemming & Courtney, 1984; Marsh, 1986).

e. Teenager/ adolescent

An adolescent or a teenager is a young person, usually between the ages 13 and 19 who has undergone puberty but has not reached full maturity (Behr, Cherian, Mwamwenda, Ndaba & Ramphal, 1986). Traditionally, adolescence/teenage-hood has been regarded as a prelude to and preparation for adulthood, a transitional period of life between immaturity and maturity, as well as having to deal with the question of "who am I?" and "Who will I be?" (Gross & McIlveen, 1998). The terms, *adolescent* and *teenager* have been used synonymously in this study.

f. Attitudes

Attitudes are described as learned cognitive, affective, and behavioural predispositions to respond positively or negatively to certain objects, situations, institutions, concepts or persons (Aiken, 2002).

2.3. Theoretical Framework

2.3.1. Theories on the origin of albinism in Africa

(a) Biological origin of albinism

Biologically, albinism is an inherited condition where the pigment melanin is lacking in some parts of the body. This affects the eyes, skin, and/or hair. There are several types of albinism; however, two main classifications dominate the field, namely, Oculocutaneous albinism (OCA) and Ocular albinism (OA). Oculocutaneous albinism is a rare genetically inherited condition passed on by both parents to their offspring, resulting in a significant reduction in or absence of pigmentation in the hair, skin, and eyes. Individuals with albinism are very fair-skinned and fair-haired with, more often than not, blue eyes that can take on tones of purple or red in bright lightning (Boyd & Asmov, 1955). The main types of this form of albinism are tyrosinase-negative and tyrosinase-positive. In the tyrosinase-negative, there is no melanin pigmentation at all, and there is a very severe vision problem. In the tyrosinase-positive type, there is little melanin resulting in some skin and hair pigmentation. The eyes also have some pigmentation resulting in less severity of vision problem. The result from this genetic defect is an enzyme called tyrosinase. Tyrosinase helps the body transform tyrosine, an amino acid, to a pigment

(Khan, 2005). The tyrosinase-negative type is prevalent among the Bapedi group of South Africa at a frequency of about 1:1500 (Lund, Maluleke, Gaigher & Gaigher, 2007).

Melanin is a colouring pigment in the skin. It is a dark-brownish pigment that is produced in different amounts in special cells in the skin. Its function is to protect the skin against damage by the ultraviolet light from the sun. Lack of melanin in tyrosinase-negative albinism leads the individuals to be very sensitive to sunlight. This means that staying in a sunny environment is hazardous for such individuals, who may suffer sunburn and skin cancer from such exposure (Schulz, 1998). Under the tropical sunshine, their melanin-deficient skin develops wrinkles, lentigines, actinic keratoses, and epitheliomata from which they may die in early adult life or in middle age.

Ocular albinism, on the other hand, only involves the eyes, causing vision defects. It severely reduces the visual clearness (visual acuity) due to abnormal development of the fovea (foveal hypoplasia), an area of the retina that receives the sharpest light images. Due to the absence of melanin in the eye during early development, this area is poorly developed. Another factor is that certain optic nerve fibres that were not supposed to cross to the opposite side of the brain do so, consequently affecting vision. In humans, about half of the optic nerve fibres from the eyes destined for the visual cortex of the brain crosses to the opposite side of the chiasma. Others pass directly to the brain of the side of the eye without crossing. In individuals with albinism, most of the fibres cross and pass to the opposite visual cortex; hence only little fibres pass to the brain on the side of the eye. This abnormality in crossing of the optic chiasma, usually referred to as

“abnormal routing”, affects certain aspects of vision (Biswas & Lloyd, 1999). Many of the eye problems are very similar to those of oculocutaneous albinism. For the child to have albinism, both parents must possess the gene for albinism. The chances of having a baby with albinism when both of the parents have the gene are one out of four per pregnancy (Khan, 2005).

(b) Exodus and multiplication of people with albinism in Africa

People with albinism came into existence thousand years ago (Winsor, 2003). Historians revealed that trying to understand the origin of human beings in ancient Africa was the most controversial and most difficult experience because most people lacked knowledge about the consequences of inbreeding and did not understand why offsprings were born with “white skin”.

Due to such lack of knowledge of why “white skinned” offspring came about, parents of such children became fearful, suspicious and began to separate their growing “white skinned” population away from the “black skinned” population. This eventually resulted into the formation of “colonies” dominated by people with albinism who then migrated northward to Europe, to escape the intensity of the equatorial sun of the southern hemisphere and seek the climatically hospitable living environment (Welsing, 1991). The people with albinism later moved in the mountainous areas during the Glaciation period, which lasted for thousand of years, further isolating themselves from their original parent population in Africa. Being in such isolated living conditions for such a long time, they

also interbred, thereby creating additional offsprings with albinism who were then and still are direct descendents of African mothers and fathers (Hardaway, 2003).

2.3.2. Theories on self-esteem and attitudes

(a) Self-esteem theory

Self-esteem theory (Samuels, 1977) postulates that individuals have a need for positive self-esteem, which is satisfied by the approval they receive from others and are frustrated by their disapproval. This theory assumes that individuals have a need to enhance their self-evaluation and to increase, maintain, or confirm their feelings of worth. In this case, a person would respond positively to positive evaluation of self, which is assumed to satisfy esteem needs and to respond unfavourably to negative evaluation of self, which would frustrate the esteem needs. The development of self begins by the baby's direct interaction with incoming stimuli. The child's behaviour "mirrors" the environment. These mirroring responses include admiration and approval. When this is lacking, the child turns to self stimulation (Samuels, 1977).

Self-esteem in children refers to the extent to which children expect to be accepted and valued by the adults and peers who are important to them. Children with a healthy sense of self-esteem feel that the important adults in their lives accept them, care about them, and are able to go out of their way to ensure that they are safe and well. Young children's self-esteem is based largely on their perceptions of how the important adults in their lives judge them. If children realize that they are judged and not cared for as expected, they will not have positive self-esteem (Samuels, 1977).

According to Mead (1967), self-esteem is derived from the reflected appraisal of others. The gauge of self-evaluation is a mirror image of the criteria employed by the important persons of the social world. He further maintains that children internalize these criteria, observe how they themselves are regarded, and value themselves accordingly. In other words, Mead (1967) points out that no one is an island when it comes to self-appraisal. No matter how isolated and independent people may believe themselves to be, they carry within them the reflecting mirror of their social group. If they place high value on themselves, there have been key persons in their lives who have treated them with concern and respect; if they hold themselves lowly, significant others have treated them as inferior people. Mead (1967) concludes that how people view themselves is primarily determined by how their significant others view them.

Lund and Gaigher (2002) also state that interaction with other individuals can sometimes boost one's self-esteem. One factor which contributes to the physical and social isolation of children with albinism is sunlight. Due to the extreme sensitivity to sunlight, these children are sometimes constrained in terms of having 'fun' with others. Again, this appears to have a negative impact on the development of self-esteem obtained through the dynamics of group and team activities.

(b) Abraham Maslow's self-actualization theory

According to Maslow (1954), each and every individual has a potential to grow and be actualized. To him, self-actualization may be loosely described as full use and exploitation of talents, capacities, potentialities, etc. However, this condition can only be

reached if a conducive environment is created for each individual. Unfortunately, due to certain environmental factors, certain conditions can hinder people's progress towards self-actualization. Factors that can hinder one's ability to be actualized include negative self-concept, low self-esteem, poor self-worth, and absence of self-acceptance. These factors may be influenced by external factors such as other people's attitudes and behaviours.

These external influences have a very great impact on how people emotionally respond to the stimuli because these personal responses shape people and their ability to adapt to different conditions. However, these responses are mainly aggravated by cultural factors which differ from one nation to another. Maslow (1968) devised the hierarchical structure, in which all lower needs have to be fulfilled before a person can reach the level of self-actualization. He further states that a self-actualized person is someone who has already satisfied all the lower needs of safety, belonging, love, and respect and has turned to fulfilling a higher need. Like others, individuals with oculocutaneous albinism need to go through this level to be satisfied irrespective of their condition.

According to Felker (1974), all human beings want to belong and every individual is born into a social setting. If individuals do not have other human beings around them to nurture them, they die. In Maslow's perspective, to belong means that an individual is a part of a group and is accepted and valued by other members of that group. However, to belong requires a mutual sense of oneness. For self-esteem to be operative, it is not necessary that the group regard individuals in this way, but that individuals regard

themselves as belonging. They must see themselves as accepted and valued members of the group. According to Maslow (1968), the need for safety, belongingness, love relations, and respect can be satisfied by other people; i.e., only from the outside person. This can be observed in social groups or communities that greatly depend on the environment. People in this dependant position cannot be said to be governing themselves, or in control of their own fate. Most people falling under this category are those governed by culture and tradition for their growth. Most Black African populations are not excluded from this category even though there are still those who are less dependent on the environment. Those who depend less on the environment are self-actualizing individuals who are far more self-sufficient and self-contained. The determinants which govern them are primarily the inner ones, rather than the social or environmental. Unfortunately, fulfilment of basic needs determines if an individual can be self-actualized or not. It is therefore of utmost importance at this stage that there is a great acceptance and love to all children if communities are to give them opportunities to be actualized (Maslow, 1968).

(c) Vrey and self-actualization theory

Vrey (1979) defines self-actualization as a person's deliberate attempts to realize all the talent potential of self. This includes every terrain of physical skills, intellectual ability, emotional experience, and moral awareness, enabling an individual to acquire and actualize the human self. Vrey suggests that an individual or a child who is self-actualized should reject negative self-concept and self-perception. Unlike adults, self-actualization in children focuses on the development of positive self-concept, since this

will enable self-acceptance that releases psychological vitality to grow towards the metaneeds. Vrey further states that if children, despite environmental challenges, can reject negative self-concept and self-perception, then they can be fulfilled and become everything they are capable of becoming.

The extent to which children can actualize themselves in a meaningful life style is determined by the extent to which parents/society as primary guide succeed in supporting them toward the significant attribution of meaning, purposeful involvement and positive experience of the self as a unique being with unique vocation (Vrey, 1979). Therefore, the society's attitudes towards children can serve as determinants of their success or failure in actualizing themselves. This means that negative attitudes towards these children will harm them, thus hindering their normal psychological growth while the positive attitudes will help them to develop well and actualize.

To add on this, Hewitt (1991) maintains that one cannot be self-actualized if one has a low self-esteem and a negative self-concept. People are led to see themselves in negative as well as positive ways through their experiences with others. In other words, people are greatly influenced by the individuals with whom they associate. Berk (2003) supports these views by maintaining that positive self-esteem in children is built by warm, positive parenting, which makes these children feel that they are accepted as competent and worthwhile. That, in simpler terms, means that the environment is responsible in building up children's self. According to Shaffer (1988), the self is initially not in existence at birth, but rises in the process of social development. This implies that any child who is

neglected and is not shown love by parents will certainly encounter problems with regard to the development of self-esteem (Gaigher, Lund & Makuya, 2002).

(d) Theories of attitudes and beliefs

An attitude can be described as learned predisposition to respond in a consistently favourable or unfavourable manner with respect to a given object. Attitude is typically viewed as a latent or underlying variable that is assumed to influence behaviour. It strongly influences social thought, the way in which people think about and process social information. It also functions as schemas-cognitive frameworks that hold and organize information about specific concepts, situations or events. Attitudes involve what people think about, feel about, and how they would like to behave towards an attitude object. This means that attitudes towards other people are acquired through experience and are, therefore, learned (Baron & Byrne, 1997).

(e) Social learning theory and acquisition of attitudes

Social learning theory postulates that attitudes are acquired from other people through the process of social learning. This means that people's views are acquired in situations where they interact with others or merely observe their behaviours. The following are types of learning people acquire in their environment:

- *Classical conditioning: Learning based on association*

This is the basic form of learning in which one stimulus, initially neutral, acquires the capacity to evoke reactions through repeated pairing with another. This suggests that

attitudes toward initially neutral stimuli can be acquired through classical conditioning (Baron & Byrne, 1997). For example, if a young child sees her mother frown and show other signs of displeasure each time the mother encounters a person with albinism, the child may be influenced. At first, the child is quite neutral toward members of this group despite their visible characteristic, but after these visible characteristics are paired or associated with the mother's negative emotional reactions, classical conditioning occurs. Gradually, the child reacts negatively to these stimuli, and to members of this group.

- *Instrumental conditioning*

Instrumental conditioning is the basic form of learning in which responses that lead to positive outcomes or that permit avoidance of negative outcomes are strengthened. Children, for instance, can be praised or rewarded in various ways by their parents or significant others for stating particular views or behaving in a particular way after having had an encounter with a person of a particular group. Normally, behaviours followed by positive outcomes are strengthened and tend to be repeated. In contrast, behaviours that are followed by negative outcomes are weakened, or at least suppressed (Baron & Byrne, 1997). For example, if the community is behaving in a particular way towards people with albinism due to cultural factors, the child who also conforms will be rewarded, thus maintaining a particular trend.

- *Modelling: Learning by example*

Another process through which attitudes are formed can operate even when parents or significant others have no desire to transmit specific views to their children. This process

is modelling, in which individuals acquire new forms of behaviour merely through observing the actions of others. Where attitude formation is concerned, modelling appears to play an important role. In many cases, children hear their parents saying things not intended for their ears, or observe their parents engaging in actions the parents tell them not to perform (Baron & Byrne, 1997).

- *Social comparison and attitude formation*

While many attitudes are formed through social learning, this is not the only way in which they are acquired. Another mechanism involves social comparison, the tendency to compare ourselves with others in order to determine whether our view of social reality is correct or not (Festinger, 1954). To the extent that our views agree with those of others, people conclude that our ideas and attitudes are accurate; after all, if others hold the same views, the views *must* be right. Because of the operation of this process, individuals often change our attitudes so as to hold views closer to those of others. For example, children might hear individual they like and respect expressing negative views towards people with albinism. This will influence their views, making them adopt similar attitudes even if they have not met a member of the group in question.

- *Prejudice and discrimination*

Baron and Byrne (1997) refer to prejudice as a special type of attitude, generally a negative one towards members of some social group. Discrimination, on the other hand, refers to the negative actions towards those individuals. In other words, a person who is prejudiced toward some social group tends to evaluate its members in a specific manner,

merely because they belong to that particular group. Because prejudice is a special kind of attitude, it may then involve more than mere negative evaluations of the groups toward whom it is directed. It may also include negative feelings or emotions on the part of the prejudiced persons when they are in the presence of, or merely thinking about, members of the group they dislike.

Prejudice may also involve beliefs and expectations about members of these groups, specifically, *stereotypes* suggesting that all members of these groups demonstrate certain characteristics and behave in a certain way. This involves generalizations about the typical or “modal” characteristics of members of various groups (Baron & Byrne, 1997). In others, they suggest that all members of such groups possess certain traits at least to some degree as it is the case of people with albinism. For example, it is stereotypical to state or assume that all people with albinism are mentally retarded, despite research findings stating that people with albinism have average intellectual maturity with similar range to that of matched control group (Kromberg & Jenkins, 1982). On the other hand, prejudice is also related to, and involves, certain aspects of *social cognition*. This is basically about the ways in which people notice, store, recall, and later use information about others in various ways, e.g. in making judgments about them. As mentioned earlier, the central component in prejudice is stereotype. Baron and Byrne (1997) further maintain that like other cognitive frameworks, stereotypes exert strong effect on how social information is processed. For example, information relevant to an activated stereotype is processed more quickly than information unrelated to it. Stereotypes lead those holding them to pay attention to specific types of information, usually information

related with the stereotypes. When the information is *inconsistent* with stereotypes held, it may be refuted or even simply denied. When activated, stereotypes allow individuals to make quick and unpleasant judgments about others without engaging in complex and more effortful thought.

- *Belief formation*

According to Fishbein and Ajzen (1975), beliefs represent the information a person has about the object. The object of belief may be a person, a group of people or an institution, etc. With respect to any object-attribution, people may differ in their belief strength. In other words, they may differ in terms of the perceived likelihood that the object has or is associated with the attribute in question.

Many of people's beliefs are formed neither on the basis of direct experience with the object of the belief nor by way of some inference process. Instead, people often accept information about some object provided by an outside source. Such sources include newspapers, books magazines, radio, and television, friends and even relatives or the larger community. Most beliefs that people hold are inferential. In other words, individuals have a tendency of using residues of past experience to make judgments (Fishbein & Ajzen, 1975).

2.4. Conclusion

The theories discussed above explained the biological origin of oculocutaneous albinism, external factors affecting self-esteem, and the causes of attitudes. It was indicated that

self-esteem does not exist at birth, but rises in the process of development and that attitudes are learned. For this reason, this study seeks to explore the self-esteem of teenagers with oculocutaneous albinism and various perceived attitudes towards individuals with the condition in the Black African communities.

CHAPTER THREE

LITERATURE REVIEW

3.1. Introduction

This chapter focuses on the literature about oculocutaneous albinism. It mainly focuses on the self-esteem of teenagers with oculocutaneous albinism and perceived attitudes of people towards individuals with the condition.

3.2. Albinism and self-esteem

The manner in which a family responds to the birth of children with oculocutaneous albinism, either positive or negative, influences society's response to the condition of these children. This means that if children with albinism are nurtured in environments where they are regarded and treated as individuals rather than stereotypes, if raised to be assertive and be self-confident, then they may strive towards their self-actualization. Therefore, societal responses sometimes determine how the children view their own self-worth (Ezeilo, 1989; Lund, 1997). According to Fox, Colhaun, Meredith and Hill (2007), teenagers with oculocutaneous albinism have a tendency of isolating themselves and as such, their self-esteem seems to be gradually eroded in their developmental process. Hence, Ezeilo's findings (1989) indicate that individuals with oculocutaneous albinism have weaker and less assertive personalities. However, in the early years of development and throughout life, family and close relatives can counter this isolation by acceptance and unconditional love. Such acceptance of an individual as a whole is vital because it is

the foundation for a lifetime of self-esteem and inner strength (Lund, 1997; Seeretsi, 2006; Waugh, 2005).

3.3. Perceived societal attitudes

(a) Perceived attitudes of the community members

As a result of the unusual appearance and symptoms which are particularly striking in the Black African population, oculocutaneous albinism is surrounded by many tales and myths. These appear to have led to the discrimination and lack of acceptance of individuals with the condition by various Black African communities. Myths about oculocutaneous albinism in South Africa are associated with birth, life, and death. Some of the myths range from gods' punishment to conception during menstruation, frightening sights during pregnancy, or eating too much during pregnancy (Okoro, 1975; Sacharowitz, 1999).

Such myths and attitudes are sometimes coupled with stigma, prejudice and assumptions of cultural beliefs. Traditionally, people with oculocutaneous albinism were killed at birth because they were regarded as a curse from the gods. Some members of the medical profession have also been known to recommend abortions to mothers carrying babies with oculocutaneous albinism because it was thought that these children would die at an early age and would not lead productive lives (King, Summers, Haefemeyer & Leroy, 2005; Machipisa, 2002; Okoro, 1975; Sacharowitz, 1999). In some rural villages, people with oculocutaneous albinism were shunned as they were thought to be products of witchcraft (Montgomery, 2004). This was the reason a family would choose to kill the

baby for fear of being labelled witches. Previously, people with the condition were also thought to be the product of interracial coupling or incest (Montgomery, 2004). Some labelled people with oculocutaneous albinism as mentally retarded. Others said the following: they can see in the dark; they can tell the future; they have supernatural powers such as mind-reading; they are contagious; they are sterile, and they have a short life span (Small, 1998). Some people even believed that a woman would have a child with oculocutaneous albinism if she sees an individual with the condition during pregnancy and does not spit between her breasts (Montgomery, 2004).

Many people with oculocutaneous albinism were institutionalized and/or stripped off vocational opportunities (King, Summers, Haefemeyer & Leroy, 2005). This was done due to the misguided belief that the low vision accompanying the condition prevented them from being functional in the society. One of many other beliefs about people with oculocutaneous albinism is that they do not die but simply disappear or “vanish” in elephant grass along river banks “when the time is ripe”. In most cases if a person with albinism died at home, he/she was not given a proper burial as it was believed that the individual did not take a proper route to go to the gods (Ka Masiba, 2005: p.9). This myth seems to be associated with the perception of white colour in the Black African community. According to Kromberg and Jenkins (1984), Black South African groups attach special significance to the colour white. Diviners/traditional doctors normally wear white beads, use white goat skins to adorn the upper parts of their bodies, and often hold white cows’ tails as whisks while dancing. There is also a distinction between ‘black’ medicines, which nullify evil, and ‘white’ medicines which are soothing and purifying in

their effect. This special meaning of white colour was assumed to have been subconsciously transferred by the community to white or a child with oculocutaneous albinism born in the Black African family. It is this phenomenon that appeared to have contributed to the growth of the myth associated with the condition. If white articles are used by the diviners and are believed to have some power to bring them nearer to the spirits of the ancestors, and if the “white child” is seen as being associated with spirits, then one conclusion might be that since spirits do not die, so neither do people with oculocutaneous albinism (Kromberg & Jenkins,1984).

The media, including literature and film, also appear to have aggravated the stereotypes and myths about albinism. In most cases, the character with oculocutaneous albinism is often portrayed as villainous, deviant, supernatural or sadistic. Also some news reports and encyclopaedia articles have included false or incomplete information about albinism. These myths continue to make it difficult for the public to know the truth about oculocutaneous albinism. Therefore people relied on these myths to validate their understanding about the condition (Waugh, 2005).

(b) Perceived attitudes of peers

One of the challenges that learners with oculocutaneous albinism were experiencing in schools amongst their peers was name-calling. Name-calling has been practised for a long time. Ancient people believed in naming something so as to control it. Another reason for name-calling, teasing and insensitivity is the lack of knowledge, curiosity, a genuine desire to learn and an inability to express questions constructively (NOAH, 2005). On the

other hand, teasing and name-calling are seen as other ways in which language can be used to dehumanize individuals. According to NOAH (2005), many disabled learners and those with albinism seem to encounter a problem of name-calling during their school years. Some people tease in order to know another person better or to express affection. This kind of teasing is usually not hurtful. However, if the person being teased does not have a positive self-image, and is not comfortable with albinism, even affectionate teasing can hurt (NOAH, 2005).

Lund (2001) indicates that some learners seem to be cruel, especially to those learners who are different from them. Most of the learners with oculocutaneous albinism who participated in Lund's study expressed that they were subjected to name-calling, were ridiculed and beaten by fellow pupils. They were avoided by their peers, who often refused to sit, eat, or play with them. These appeared to be a painful experience for small children who needed physical expression of love and care and for teenagers who are looking for group interaction and acceptance (Kromberg, Zwane & Jenkins, 1987). Learners with oculocutaneous albinism were taunted with demeaning names such as "Santa Clause", "whitey", "Fluorescent face" and "District Officer". These negative attitudes appeared to have led these learners to drop out from school (Okoro, 1975; Romenesko, 2005).

(c) Perceived attitudes of teachers

South Africa has few special schools that provide individualized educational programmes for the blind and partially blind learners, majority of whom are learners with

oculocutaneous albinism (Lund & Gaigher, 2002). Since these schools were mainly designed for learners with poor eye sight, they are specially adapted to reduce glare, with shutters on the windows at one side, and a covered walkway at the other. Rooms are equipped with mobile black boards on wheels which can be moved around to the best position at different times of the day. During lessons, these learners are allowed to walk up to the board to read. All these measures help to reduce the poor vision and extreme sensitivity to sunlight. The schools also encourage and support positive attitude towards albinism, and enhance the learner's self-image and self-worth (Lund & Gaigher, 2002).

Unlike in South Africa, most of the Zimbabwe's learners with albinism are integrated into the mainstream education (Lund, 2001). The country has fewer special schools with teachers trained in the education of learners with visual impairment. South Africa today has also introduced the inclusive education where learners have rights to attend schools they wish regardless of colour, religion, or their physical condition (South African Schools Act, 2006). Consequently, most learners with oculocutaneous albinism are at liberty to attend any school of their choice.

Lack of melanin in learners with oculocutaneous albinism develops abnormalities of the eye and the visual pathway, leading to lifelong ocular problems. This includes photophobia (disabling sensitivity to bright light and glare), nystagmus (involuntary eye movement), lack of stereopsis (lack of binocular vision), and often strabismus (squint). Due to these conditions, these learners often find themselves left out of extracurricular

activities such as sport or gardening. Their visual problems also make them unable to see clearly on the black board or print in text books (Lund, 2001).

These visual problems were ones most commonly reported to affect their progress, and as a result, most of them end up dropping out of school as they might be seen as underachievers, and eventually seeking disastrous menial outdoor occupations like farming where prolonged exposure to the sun is a threat to their health. Their problems with eyesight limit the amount of time they spend to study as well as their speed of reading and writing. In a study conducted by Lund (1997: p.11), a secondary school head commented that although their learner with oculocutaneous albinism was good in all subjects, she could not study for more than an hour at a stretch because of her poor eyesight. Sometimes with the help of sympathetic teachers, these learners are provided with a free access to the teacher's "territory", which is close to the board, and sometimes are allowed to take their books and sit right underneath the board. Some teachers also permit these learners to change their sitting positions, depending on where the work is being conducted. In some instances these learners are allowed the use of their own textbooks, rather than sharing with others (Lund, 1997). However, on the other hand, it has been reported that unsympathetic teachers often order these poor-sighted learners to sit down if they happen to stand up in order to reach the chalk board (Musiwa, 1998).

According to Gaigher, Lund, and Makuya (2002), learners with oculocutaneous albinism are often isolated from activities that stimulate cognitive and perceptual motor development because they cannot take part in outdoor activities and tasks. Because of the

poor eyesight or highly sensitive skin, these learners often seem to be threatened when surrounded by the “normally sighted”, who exuberantly and confidently master new skills and play games from which they are excluded.

(d) Perceived attitudes of family members

Albinism can be found in all human races. However, it becomes more startling when it occurs in a dark-skinned people. Misunderstanding of the causes of oculocutaneous albinism was sometimes a catalyst for extra family stress. Initially, most husbands thought that their wives cheated on them with White males. This often created mistrust between couples. In extreme cases, this misunderstanding led to divorce and rejection. A recent survey shows that more than 63 percent of children with albinism contacted in Zimbabwe come from broken homes (Machipisa, 2002). In most cases, a father abandoned his family when a child with albinism was born. Those fathers who opted to stay in the family often had a tendency of treating the child harshly. The child would be treated not as a member of the family as s/he would be seen as having brought shame to the whole family (Machipisa, 2002). In some cases, if the mother is ‘stuck’ with child-care and custody, she may abuse or even abandon the child. Contrary to these families, some parents, after their initial shock, accept these children and treat them as special gifts from God. They find these ‘golden children’ attractive and are proud of them (NOAH, 2007: p.1).

3.4. Conclusion

According to the literature above, people with oculocutaneous albinism within the African context appeared to have been taunted from cradle to grave (Okoro, 1975). Their self-esteem appeared to have been low and the perceived societal attitudes towards them seemed to have been negative. The following hypotheses were drawn for the study:

3.5. Hypotheses

(a) Hypothesis to be tested quantitatively:

Teenagers with oculocutaneous albinism have low self-esteem as compared to teenagers without the condition.

(b) Assumption for the qualitative study:

The perceived societal attitudes towards teenagers with oculocutaneous albinism are negative.

CHAPTER FOUR

METHODOLOGY

4.1. Introduction

This chapter focuses on research methodology, which comprises of tools and techniques upon which the entire research was based. It includes the data collection methods, instruments, sampling and sample size, procedure used to collect data, and methods for data analysis.

4.2. Methods used

Qualitative and quantitative methods were triangulated in this study. Creswell (1994) defines triangulation as a mixed approach whereby both qualitative and quantitative research methods are used eclectically to study the same social phenomenon. This approach was used to understand the problem holistically and to offset the weaknesses inherent within one method with the strengths of the other method to overcome intrinsic biases and the problems that come from single method (Tashakkori & Teddlie, 2003).

4.2.1. Quantitative Method

Quantitative method was used in this study to identify the relationship between oculocutaneous albinism and self-esteem amongst teenagers by using the Rosenberg's Self-Esteem Scale (The Morris Rosenberg Foundation, 2006).

4.2.2. Qualitative method

Qualitative research method aims at exploring unknown sectors, identifying the main dimensions of the problem, drawn assumptions, and understanding motivations. The method derives its data from interviews or verbal interactions and focuses on the meanings and interpretations of the participants (Marks & Yardley, 2004). Qualitative method was used in this study to explore the experiences of teenagers with oculocutaneous albinism and how they perceive societal attitudes towards them.

4.3. Quantitative Approach

4.3.1. Instrument

A standardized questionnaire was used to collect data (Appendix 1, sections A & B). The questionnaire was used in this study to measure self-esteem of both teenagers with and without oculocutaneous albinism. It was designed in both English and Sepedi versions to give the participants an opportunity to respond in the language they understand best. The questionnaire consisted of two sections. The first section included items asking for basic demographic information. The second section consisted of a standardized scale of self-esteem by Rosenberg (The Morris Rosenberg Foundation, 2006).

Rosenberg self-esteem scale was developed to measure adolescents' global feelings of self-worth or self-acceptance. The scale includes 10 items that are usually scored using a four-point response ranging from strongly disagree to strongly agree. Studies have been conducted in the United States of America, and the reliability of the scale was established. The scale has high reliability: test-retest correlations are typically in the

range of 0.82 to 0.88, and Cronbach's alpha for various samples are in the range of 0.77 to 0.88 (The Morris Rosenberg Foundation, 2006). However, the Cronbach's alpha for this scale among all the participants in this study is 0.53.

The Sepedi version questionnaire was translated from English into Sepedi by a Sepedi speaking translator and then back-translated into English by another translator. The accuracy of the translation was subsequently checked by qualified high school teachers of English and Sepedi. Back-translation technique was used to ensure consistency of meaning amongst both the English and Sepedi versions of the questionnaire.

Before the final version of the questionnaire was adopted for use in this study, a pilot study was conducted. Pilot study was conducted to assess the questionnaire's level of understandability, its ability to be completed, the time it takes to be completed, as well as its reliability. The questionnaire was administered to a group of 20 learners without oculocutaneous albinism in one of the regular high schools and to a group of 10 learners with oculocutaneous albinism in one of the special high schools in the Capricorn District. Those who participated in the pilot study together with their results were excluded from the main study.

4.3.2. Sampling and sample size

The sample comprised of 100 Black African teenagers aged 13-19 years old. Twenty (40%) female and 20 (40%) male teenagers with oculocutaneous albinism were selected from one special high school, whereas, thirty (60%) female and 30 (60%) male teenagers

without the condition were selected from one regular high school in the Capricorn District. Systematic random sampling was used to select the participants for the study. Systematic sampling procedure is defined as an approach which involves drawing every x th unit from a population. This method was used so as to give a better coverage of the population without bias (Hopkins, 2000; May, 1997). In this study, class registers were collected from the class teachers in each school, one identified regular and the other special school. Initially, the names of the learners in those registers were arranged alphabetically according to the learners' surnames. The names of learners aged 13-19 were identified and written randomly in the researcher's register. Every second learner was then selected from the researcher's register.

4.3.3. Setting

Permission to conduct the study was obtained from the Department of Education, departmental circuit offices and the school managers. The learners' classrooms were used for the study.

4.3.4. Procedure

During the first meeting, participants were addressed in a classroom. The purpose of the study was explained to them. They were informed that those who were not willing to participate in the study were free to be excused. However, all learners were willing to participate. On the same day, participants were given consent forms to be signed by parents or guardians at home. The contents of the forms were fully explained to the

participants. To avoid the disruption of lessons, the researcher was given “free lessons” to conduct the study.

On other arranged dates, participants were assembled in the classrooms and the consent forms were collected. The researcher started the administration by distributing the questionnaires according to the participants’ choice of language, Sepedi or English. However, all participants in both schools requested the English version because English is used as a medium of instruction at their schools. The instructions were verbally explained to them by the researcher. The first part of the questionnaire, which was about the participant’s demographic characteristics, was done together, item by item with the researcher leading and reading out the questions to the participants. After the first part was completed, the second part was explained and participants were encouraged to work on it individually, quietly and honestly. The researcher was seated in the classroom in case the participants needed clarity on the questionnaires. To preserve the privacy of the learners, teachers were not present during the administration of the questionnaires. The questionnaires took an average of about 30 minutes to complete. They were collected and checked for missing data immediately after being completed. All questionnaires were returned, and they were all correctly filled in.

4.3.5. Methods of data analysis

The Statistical Package for Social Sciences (SPSS) was used in analyzing data, with the use of an Independent *t*-test as the statistical method of choice. This method was used to

test if the difference between the means of self-esteem of both the experimental and the control groups in the study was significant (Sapsford & Jupp, 1996).

4.4. Qualitative Approach

4.4.1. Instruments

An exploratory interview was conducted using an interview schedule or guide which consisted of open-ended questions (Appendix 2). According to Rubin and Babbie (2002), an interview guide or schedule ensures that the interviewer covers the same material and keep focused on the same predetermined topics and issues while at the same time remaining conversational and free to probe into unanticipated circumstances and responses.

Before the actual interview was conducted in the field, the researcher checked each item for relevancy to the aim and objectives of the study. Focus group interview was conducted with five learners having oculocutaneous albinism from the special school to assess the degree to which the questions on the interview guide could be understood, and the duration that might be taken for the discussion. The results of this pilot study were excluded from the main study.

4.4.2. Sampling and sample size

The sample in this study consisted of Black African teenagers with oculocutaneous albinism. The study used purposive sampling method to select 40 Black African

teenagers with oculocutaneous albinism in one special high school in the Capricorn District. These were the same subjects who also participated in the quantitative study.

Purposive sampling is a selection of information-rich cases for an in-depth study (McMillan & Schumacher, 1993). This sampling method was used for the study so that only the sample which is knowledgeable and informative about the phenomena the researcher is investigating is selected. The participants in the study were randomly selected on the basis of their condition, which is that they should have oculocutaneous albinism and that in terms of age they should be between 13-19 years. This technique was used to eliminate bias and to give every individual the same probability of selection. The sample consisted of two groups of subjects. Initially, the study intended to divide the participants' groups according to the age ranges of 13-15 years and 16-19 years. Unfortunately there were no participants in the school within the age range of 13-14 years. Then the two main groups of subjects in the study consisted of 20 (50%) participants between the age ranges of 15-17 years and 20 (50%) between the age ranges of 18-19 years. The aim of dividing participants into these age groups was to enable them to feel comfortable during discussion knowing that the members were within their age group. The two main groups were then divided into four manageable focus groups. Each group consisted of 10 members, both male and females as arranged by their age groups.

Terreblanche and Durrheim (1999) define a focus group as a group of people who share similar type of experience, but that is not "naturally" constituted as an existing social group. Focus group was used to enable the researcher to explore the experiences of those teenagers with oculocutaneous albinism, and to empower group members in the process.

This method was also used to enable the researcher to learn through discussion about conscious, semiconscious, unconscious psychological characteristics and processes among group members (Berg, 1995).

4.4.3. Setting

The study was conducted in the special school, situated within the Capricorn District. This is the only special high school within the Polokwane Municipality, consisting of learners who have hearing and visual problems. To have access to this institution, permission was obtained from the Provincial Department of Education in Polokwane and the principal of the institution. The researcher conducted the interviews in vacant classrooms where activities were not disrupted.

4.4.4. Procedure

The majority of participants in this regard were boarders. To avoid disruption of normal lessons, the study was conducted after school. The boarding personnel were contacted for access to learners in their hostels.

During the first meeting, participants were assembled in the hall. The purpose of the study and the procedures, including the use of a tape-recorder during the discussions were explained to them. Those who were willing to participate in the study were given the consent forms to give to their parents/guardians. The contents of the consent forms were fully explained to the participants. On another arranged date, the participants were assembled again in the hall. The consent forms from parents/guardians together with those of participants who were 19 years old were collected.

On the same day, participants were divided into focus groups of 10 each. Appointment dates were arranged for each focus group and discussions took place as arranged. For each session, participants were assembled in a vacant classroom. To enable the participants to express themselves freely and adequately, the interviews were conducted in the participants' home language which is Sepedi. The interviews were transcribed into English immediately after the session. The interview format used was that of an explorative clinical interview, which aimed at interviewing the participants with an empathetic understanding of their predicament. The researcher facilitated the focus groups following the steps below as proposed by Krueger (1994):

- The researcher introduced herself and welcomed the participants.
- Group members introduced themselves.
- An overview of the topic was given.
- Ground rules were established.
- Uncertainties/ concerns from participants were checked.
- Questions were asked by the researcher as guided by the interview schedule, which appears in Appendix 2.
- Before the end of each session, the researcher thanked the group for their participation, stressed how helpful the discussion had been and also reaffirmed confidentiality.

The discussions took an average of 1 (one) hour for each group. This prolonged engagement with the participants was aimed at identifying recurring themes.

4.4.5. Methods of data analysis

To analyze the data, the researcher used the interpretative phenomenological analysis. An interpretative phenomenological-based approach was appropriate for the study as it intended to bring out to the forefront the everyday experiences of this group as presented during the interview. The researcher adopted Van Manen's (1990) six steps of phenomenological analysis. The following are Van Manen's six steps of phenomenological analysis that were followed:

- The researcher repeatedly read the participants' descriptions until the researcher was familiar with what has been said.
- The second step was re-reading the data, identifying and highlighting meaningful phrases, statements or words that seemed to be important for the phenomena being studied.
- Each significant statement was noted.
- Different statements were organized into clusters of themes. Common or similar themes of meanings were identified and grouped together.
- The researcher tried to find links between the themes and then described and summarized them.
- Regularities and sets of similar ideas were grouped into sub-themes and were then compared (Van Manen, 1990, p.85).

4.5. Ethical Consideration

Ethics are rules that suggest expectations about the most correct conduct towards experimental subjects (Vadum & Rankin, 1998). To ensure that the researcher was operating within expected research ethics limits, the following research ethical standards as stipulated by the American Psychological Association in 1983 and the University of Limpopo Ethics Committee were adhered to:

- **Confidentiality:** Information about the subjects was kept confidential.
- **Consent:** Rights of participants were respected. They were provided with an explanation of the research, and they were told that they were at liberty to terminate their participation if they did not feel comfortable, although they were encouraged to participate. Parents or guardians signed consent forms on behalf of participants who were below the age of 19 years. Those who were 19 years signed the consent forms for themselves.
- **No harm:** The researcher ensured that the participants were protected from physical and mental discomfort, harm, and danger. Because the study was about sensitive emotional issues, prior arrangements with a registered counsellor were made for counselling in case of any mental discomfort to any of the participants.
- **Honesty:** The researcher tried to be as open as possible with the participants.

4.6. Conclusion

Research design, sample for the study, procedure followed in collecting data, measurement instruments and statistical analysis followed in this study was discussed in this chapter. The results of the study will therefore be presented in the next chapter.

CHAPTER FIVE

RESULTS

5.1. Introduction

This chapter mainly focuses on the presentation of results as well as the testing of the hypotheses.

5.2. Quantitative aspects of the results

5.2.1. Demographic details of the participants

Table 1: Demographic details of participants

Items	Participants with oculocutaneous albinism		Participants without oculocutaneous albinism	
	N	%	N	%
Gender:				
Males	20	40.0%	30	60.0%
Females	20	40.0%	30	60.0%
Age range:				
13-15	4	11.8%	30	88.2%
16-19	36	54.5%	30	45.5%
Participants' level of education:				
Grade 8-10	24	29.3%	58	70.7%
Grade 11-12	16	88.9%	2	11.1%
Number of siblings with albinism:				
None	19	24.7%	58	75.3%
One	0	0.0%	1	100.0%
Two	15	93.8%	1	6.2%
Three and more	6	100.0%	0	0.0%
Parental marital status:				
Single	14	34.1%	27	65.9%
Married	23	45.1%	28	54.9%
Divorced	1	33.3%	2	66.7%
Deceased	2	40.0%	3	60.0%
Mother's education:				
Primary school level	5	38.5%	8	61.5%
Secondary school level	20	40.0%	30	60.0%
Post Matric	12	37.5%	20	62.5%
Father's education:				
Primary school level	1	16.7%	5	83.3%
Secondary school level	13	44.8%	16	55.2%
Post Matric	12	36.4%	21	63.6%
Guardian's education:				
Primary school level	1	100.0%	0	0.0%
Secondary school level	0	0.0%	3	100.0%
Post Matric	1	100.0%	0	0.0%

The total of 100 Black African high school learners participated in the study. Forty percent of the participants had oculocutaneous albinism, and 60.0% of them were without the condition. Most of the participants (N=51) were from intact families (i.e. with parents still married), and few (N=42) have siblings with oculocutaneous albinism. Although most of their parents are not highly educated, but the majority of them (N=82) have secondary school education (see table 1).

5.2.2. *The results*

Table 2(a) Mean and the standard deviation for the scores on the Self-Esteem Scale

Albinism status	With albinism (N=40)		Without albinism (N=60)	
	Mean	SD	Mean	SD
Self Esteem	36.08	3.116	33.57	3.259

Table 2 (b) Mean and standard deviation for the scores on the Self-Esteem Scale for males and females

		<i>n</i>	Mean	SD
Females	Albinism	20	36.80	.2238
	Normal	30	33.67	.3781
Males	Albinism	20	35.35	.3717
	Normal	30	33.47	.2700

Table 2 (a) indicates that the mean score for participants with oculocutaneous albinism is higher (Mean=36.08) than the mean score of the control group (Mean=33.57). Table 2 (b) further indicate that mean scores of males (Mean=35.35) and females (Mean=36.80) with oculocutaneous albinism are higher than mean scores of males (Mean=33.47) and females (Mean=33.67) of the control group.

Hypothesis for the quantitative aspect of the study:

“Teenagers with oculocutaneous albinism have low self-esteem as compared to teenagers without the condition.”

Table 3. An Independent *t*-test on the Rosenberg Self-Esteem Scale

df=degrees of freedom, MD=Mean Difference, SED=Standard Error Difference, CID=Confidence Interval of Difference.

	t-test for equality of means						
	t	df	Sig. (2 tailed)	MD	SED	95% CID	
						Lower	Upper
Self Esteem	3.836	98	.000	2.508	.654	1.211	3.806

The *t*-test indicates that the scores of the experimental group on Self-Esteem Scale are rather significantly higher than those of the control group ($p < 0.01$). The main hypothesis is therefore rejected. Contrary to the expectation, the participants with oculocutaneous albinism scored higher on the Self-Esteem Scale with the mean score of 36.08 as compared to the participants without oculocutaneous albinism with the mean score of 33.57.

5.3. Qualitative aspects of the results

Using the quantitative approach alone for this study would have deprived the researcher of an opportunity to get a clearer understanding of societal attitudes as perceived by teenagers with oculocutaneous albinism. The use of the qualitative approach in this

regard was deemed vital to understand the experiences of these individuals; hence the following assumption was drawn:

Assumption for the qualitative aspect of the study:

“The perceived societal attitudes towards teenagers with oculocutaneous albinism are negative.”

5.3.1. Demographic details of the participants with oculocutaneous albinism

The total of 40 (100%) Black African high school learners with oculocutaneous albinism from the special school participated in the study. Twenty participants (50%) were males and 20 (50%) were females. They were grouped into two main groups within the age ranges of 15-17 years (50%) and 18-19 years (50%). Twenty-four (60%) participants were from grade 8-10 and 16 (40%) participants were from grade 11-12.

5.3.2. The Results

The results from this approach are presented in the form of descriptions of themes that emerged from the analysis of the focus group discussions. The themes were grouped under the following categories:

- Perceived attitudes of the community members
- Perceived attitudes of peers
- Perceived attitudes of teachers
- Perceived attitudes of family members

(a) Perceived attitudes of the community members

When asked to comment about the attitudes of the community members towards them as teenagers with oculocutaneous albinism, various themes emerged as presented below:

- *Name-calling*

Name-calling was mentioned in all focus groups. Most of the participants reported that they have frequently been subjected to name-calling, especially when they were young. They indicated that this mainly occurred at regular schools they attended previously. Few participants indicated that they are still subjected to name-calling, especially when they visit communities where there are no people with the condition. They further pointed out that it is mainly small children or a few adults who called them names. This is attested by some of the following responses:

“... small children call me names such as “lekgowa” (white man), “baas” (white boss).

“Drunkards and children call me names such as “leburu” (white farmer) or “lekgowa” (white man).

“... For instance, small kids from other villages sometimes call me “mist”, “leburu”, “lehwehle” (individual with albinism in a derogatory manner).

- *Staring*

The majority of the participants indicated that some children stare at them with amazement, especially when they visit other villages. This is attested by the responses below:

“Sometimes children in other villages stare at me for a long time as if I am an alien.”

“These children will not say anything but will stare at me for a long time.”

- *Respect*

Although they reported that they are sometimes subjected to name-calling, the majority of the participants in all groups indicated that they are sometimes treated with respect by other members of the community, as the following excerpts show:

“Not all people are bad; some are nice to me and treat me with respect.”

“There are many people with this condition in my area. Maybe that is the reason they treat me with respect like other human beings.”

- *Admiration by others*

Few female participants indicated that they are often admired because of their condition. They reported that they are mostly admired by children. This is attested by some of their responses:

“Some of these children admire my skin and my golden hair. Some wish they had albinism.”

“Sometimes children come to me and touch me. Some tell me that they wished they had long golden hair like mine.”

- *Curiosity*

Community members appear to be gradually becoming interested in knowing more about oculocutaneous albinism. This curiosity appears to be persuading them to ask many questions about the condition. Few participants indicated that they have been approached at least once by either children or some friends asking about oculocutaneous albinism. The following responses attest to that:

“...many people in my village ask me about my skin, my hair and some about the myths concerning albinism. For instance, they ask me if I have special powers. This makes me feel good because I can see that these people genuinely do not know about the condition and are prepared to learn more about it.”

“They ask me about my condition and want to know about some of the myths if they are true or not”.

(b) Perceived attitudes of peers

When asked to comment about the attitudes of their peers (i.e., those with and without the condition) towards them as individuals with oculocutaneous albinism, the following theme emerged:

- *Acceptance*

The majority of the participants reported that they feel accepted by most of their peers of both sexes. This is indicated in the following excerpts:

“My peers have accepted me. I do not have any doubt about it because they treat me well.”

“...I think they understand that I am not different from them, that is why they have accepted me.”

“I have many friends who have accepted me and understand my condition.”

“They treat me well and they love me big time.”

Although many participants reported to have been accepted by their peers, few male participants were concerned about females (especially those with oculocutaneous albinism) who sometimes reject their love proposals. This is reflected by the following responses:

“...they refuse our love proposal. It is as if they don't love us or their condition. ”

“...these girls like us but do not love us. They do not accept us the way we are.”

(c) Perceived attitudes of teachers

When asked to comment on the attitudes of teachers towards them as learners with oculocutaneous albinism, the following themes emerged:

- *Acceptance*

When commenting about the attitudes of the teachers, all the participants in all the focus groups reported to have felt accepted by their teachers, especially in the current school (special school). The following responses reflect feelings of acceptance by teachers:

“Teachers in this school (special school) have accepted and treat us with respect because it seems they have been trained about people with our condition. They treat us just like other people.”

“...Teachers in this school love us unconditionally. This makes me feel good and makes me feel that I am a normal human being just like other children.”

“They give us the warm treatment, just like their own children”.

Contrary to the attitudes of teachers in the special school, most of the participants indicated that they were subjected to negative attitudes of some of the teachers in regular schools they attended previously. This is reflected by the following excerpts:

“One lady teacher did not really like me. She was harsh to me and she sometimes commented badly about my condition.”

“Some teachers were irritable especially if I did not see well on the board.”

“This pregnant lady teacher was rude and insensitive and sometimes I would even see her spitting on her breast when she sees me.”

- *Discrimination*

The majority of the participants reported that they felt they were directly discriminated against by some of the teachers who did not understand their condition in regular schools they attended before:

“... It was as if I was not part of the learners. I always felt discriminated against until I came here.”

“...their comments sometimes made me feel as if I am not a Black person. I felt I was discriminated against.”

(d) Perceived attitudes of family members.

The two following themes emerged when the participants were asked to comment on the attitudes of their family members:

- *Acceptance*

The majority of the participants indicated that they feel comfortable in their families. They reported that their family members and their relatives accept their condition and love them unconditionally. This is attested by their responses:

“Everybody in my family understands my condition and accepts me.”

“My parents and my relatives love me. They treat me normally just like my siblings and everyone else in the family.”

“I am the only one in the family with albinism but my parents, siblings and my relatives accept me. They treat me well just like any other child in the family.”

“...they love me unconditionally.”

- *Overprotection*

Most of the participants raised a concern about their parents who appear to be more concerned about their condition and overprotective of them as compared to their siblings. This is attested by the following responses:

“My parents are overprotective and always remind me to put on a hat and sunscreen.”

“They are too concerned about my condition, but otherwise they treat me well.”

Few male participants reported that their parents' overprotection sometimes makes them feel they are irresponsible and could not take care of themselves. This is reflected by the following excerpts:

"It is like I am still a child who cannot take care of myself."

"...this is making me feel as if I do not know and understand my condition, or it is as if I am irresponsible despite the fact that I am the eldest in the family."

5.4. Conclusion from the qualitative analysis

The findings from the qualitative aspect of the study suggest that the perceived attitudes of community members and the teachers towards teenagers with oculocutaneous albinism are mixed (i.e. both negative and positive), whereas the perceived attitudes of the peers and family members are positive. These perceived mixed attitudes in the Black African communities gives a clear indication that although people have developed perceived positive attitudes, there are still some perceived negative attitudes towards individuals with oculocutaneous albinism which appear to hinder progress in total acceptance and understanding of the condition.

CHAPTER SIX

DISCUSSION AND CONCLUSION

6.1. Introduction

This chapter presents discussions of the major findings of the study in relation to the literature review and self-esteem theories. It concludes by commenting briefly on the limitations of the study and offers recommendations.

6.2. Discussion of the Quantitative data

(a) Self-esteem

Findings in this study indicate that teenagers with oculocutaneous albinism have higher self-esteem compared to those without the condition. This is indicated by the high self-esteem score (Mean=36.08) of the experimental group compared to the low self-esteem score (Mean=33.57) of the control group on the Rosenberg self-esteem scale. These findings concur with the findings by Kromberg and Jenkins (1984). The findings in both studies suggest that teenagers with oculocutaneous albinism are satisfied with their self-image more than those without the condition. The implication of these findings is that individuals with oculocutaneous albinism have a sense of self-worth which could be emanating from positive self-perception as stated by participants in the current study when they sometimes regard themselves as “unique”. According to Ezeilo (1989), such positive self-perception is important because if individuals with oculocutaneous albinism, (in spite of their physical and visual problems) perceive themselves more positively and learn to be more assertive, then society may gradually learn to relate to them more

positively than is often the case. Kromberg and Jenkins (1984) further state that such positive self-perception of these individuals could have also been nourished by socio-cultural factors. For instance, in the Black African culture, people associate oculocutaneous albinism with the characteristics attributed to whiteness, such as cleanliness, purity and goodness, which are held in high esteem by the rural Black African groups.

6.3. Discussion of the Qualitative data

(a) Perceived attitudes of the community members

Prior to the study, the researcher hypothesized that the Black African communities have completely negative attitudes towards people with oculocutaneous albinism. From the findings, however, perceived attitudes of such communities are mixed. Negative attitudes reported by the participants include name-calling and being stared at by children. According to the report by NOAH (2005), name-calling results from lack of knowledge and inability to express questions constructively. For instance, children become startled when they see people who are different from them for the first time. With an inability to express their concern and questions constructively, they then call these individuals names. Being stared at was also found to be a common experience of individuals with the oculocutaneous albinism even in the previous studies (Lund, 2001). This reaction was explained to be caused by fear and inadequate understanding of the condition. In response to these negative attitudes, participants reported to be rejecting devaluation by “ignoring negative comments and not taking them to heart”. According to Rosenberg (1965), individuals have such ability to defend 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 worthiness, ability, and power.

The results also revealed the perceived positive attitudes of community members towards teenagers with oculocutaneous albinism. These include respect, admiration by others, and curiosity. Despite the presence of perceived negative attitudes, participants reported that they are respected by some members of their communities. This finding 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. Respect towards individuals with oculocutaneous albinism could be emanating from the Black South African belief that if one is unkind to anyone with the condition, he/she will later bear such child (Kromberg & Jenkins, 1984; Lund, 1997).

The findings further revealed that teenagers with oculocutaneous albinism are admired especially by children because of their unusual appearance. The assumption for such admiration could be that most of “golden children” (NOAH, 2007, p.1) are found to be attractive because they use sunscreen lotions and have blonde hair of which when straightened seems to give an individual a unique look. This is contrary to the previous findings. In the 1980’s (Kromberg, 1987), these individuals were not admired as their melanin-deficient skin often developed wrinkles, lentigines, actinic keratoses and epitheliomata. They were also not admired because there were many negative myths attached to them. Some of the myths were that they are mentally retarded, sterile, dangerous and have short life span (Small, 1998; Montgomery, 2004).

Awareness campaigns appear to play a vital role in generating and increasing the desire of community members to know more about the condition, hence the findings show that a number of community members are curious about the condition. Some of the campaigners include the Albinism Society of South Africa (ASSA), the Department of Health (sub-directorate of human genetics), Developmental Bank of Southern Africa and *The Sowetan* newspaper. These four organizations introduced a National School Essay competition on albinism since 2002. The competition is open to grade 11 to 12 learners with the aim of raising awareness and “quashing all imaginable myths and superstition about albinism” (Mocoamere, 2007, p.16). Such activities and dedication of September as an albinism month promote awareness and increase the level of societal curiosity about the condition. This implies that as long as people are curious and information resources are provided, chances are high that in future, myths and certain unpleasant attitudes towards people with oculocutaneous albinism will disappear.

(b) Perceived attitudes of peers

The findings indicate that peers accept teenagers with oculocutaneous albinism and seem to understand their condition. This is contrary to previous findings (Lund, 2001) where teenagers with the condition were avoided by their peers who refused to sit, eat, or play with them. This was seen as an unhealthy attitude (Lund & Gaigher, 2002) which denied these teenagers an interactional opportunity which could boost their self-esteem. Although they indicated that they feel accepted by their peers, few male participants were concerned about the rejection of their love proposal especially by the female teenagers with the condition. In response to this, female participants indicated that they do not

prefer partners with oculocutaneous albinism because they have the “albinism gene” which might lead them to have children with the condition. This finding is in line with Gaigher, Lund and Makuya’ study (2002) who further revealed that females with the condition are also skeptical to marry partners with the same condition fearing that due to their condition, they might both not be able to secure jobs in future.

(c) Perceived attitudes of teachers

Findings revealed that learners with oculocutaneous albinism experience “warm treatment” from the teachers in the special school. When elaborating on the “warm treatment”, they indicated that unlike teachers in the mainstream schools, those in the special school understand their condition. These results concur with the findings by Lund and Gaigher (2002), where special schools were rated high by participants with oculocutaneous albinism. These schools were preferred because special adaptations were made to the classrooms, and the teachers were aware of the participants’ visual impairment. The findings further indicate that a special school is also preferred because it encourages and supports positive attitudes towards albinism. These findings are in line with the self-esteem theory (Samuels, 1977) which postulates that a healthy self-esteem in learners develop as a result of acceptance by teachers who care for them and who would go out of their way to ensure that learners are safe and well. Although, teachers cannot naturally, be expected to love their pupils in the same way as a child in the family, Siann and Ugwuegbu (1980) believe that a warm accepting teacher provides a background that is conducive to learning and vital in the development of self-concept and self-esteem.

(d) Perceived attitudes of family members

The results reveal that teenagers with oculocutaneous albinism feel accepted by their family members. They further reported that it is this acceptance that maintains their self-esteem. This finding concurs with the study conducted by Gaigher, Lund and Makuya (2002). Both findings are supported by Berk's (2003) idea that self-esteem in children is built by warm, positive parenting which makes them feel accepted as competent and worthwhile individuals. Even though they feel accepted, the study by Kromberg, Zwane, and Jenkins (1987) indicates that the process of acceptance of children with oculocutaneous albinism by parents, especially the mothers occurs slowly.

Current findings on parental acceptance are contrary to the previous report by Machipisa (2002). He mentioned in his report that the birth of a child born with this condition often caused conflicts in families, and sometimes led the fathers to reject the child or abandon their families. His report was supported by a survey of the Zimbabwe Albino Association which showed that most of the people with albinism (63%) were from the broken homes (Machipisa, 2002). Findings in the current study, however, show that out of 40 participants with oculocutaneous albinism, twenty-three (57.5%) of them are staying with both their parents who are married. This may therefore mean that perceived attitudes of parents towards children with oculocutaneous albinism are gradually heading towards a positive change.

Education and genetic counseling offered by the Department of Health and other outreach clinical genetic programmes in rural areas seems to be assisting parents in the

management of the different genetic conditions, including oculocutaneous albinism (Christianson, 1999). With such knowledge, parents seem to be prepared to maintain their children's health; hence, they are more concerned and overprotective as indicated by the findings in the current study. The participants' concern about their parental overprotection could have also been raised by peer image which might have lessened their interest in wearing protective clothes and thus contradicting with their parental wishes. For instance, most of them do not wear protective clothes such as the legionnaire-style cap with a long flap at the back because they consider them to be ugly (Lund & Gaigher, 2002).

Some of the contradictions between the findings in the previous studies and this study imply that perceived societal attitudes towards people with oculocutaneous albinism have undergone change in the last century. Therefore ignorance, superstitions, and infanticide appear to be gradually replaced by understanding, acceptance, and sometimes overprotection (Kromberg, Zwane, & Jenkins, 1987).

6.4. Summary of quantitative and qualitative discussion

Findings from both the quantitative and the qualitative approaches have provided a rich and important information to the study. It is interesting to note that teenagers with oculocutaneous albinism have high self-esteem. This is contrary to the previous findings which showed that these individuals had weaker and less assertive personalities (Ezeilo, 1989). Such change implies that these individuals are gradually developing more sense of self-worth irrespective of their condition. The study also indicates that community

members and teachers have mixed attitudes, whereas the peers and family members have positive attitudes towards teenagers with oculocutaneous albinism. The implication of this finding is that even though there seem to be a steady growth in understanding and acceptance of oculocutaneous albinism, there are still some reservations in the Black African communities with regard to the condition.

6.5. Conclusion

High self-esteem of teenagers with oculocutaneous albinism suggests that the positive way these individuals see, think, and feel about themselves enables them to be assertive and eventually strive towards self-actualization. This positive self-perception is important because it also influences other people's perception and attitudes towards teenagers with oculocutaneous albinism.

6.6. Limitations of the study

The results of this study should be interpreted cautiously due to the following limitations:

- Since this phenomenon has not been well-researched in South Africa, reference was based on studies conducted in other countries.
- All participants with oculocutaneous albinism in this study were found only in a special school. Thus, generalization to others with the same condition should be done with caution.

- The fact that the interviews took place at the schools may have restrained the participants from revealing problems experienced at schools, thus biasing the findings to some degree.
- The instrument used to measure the participants' self-esteem in this study was originally adopted for the cultural group different from the current sample; hence the Cronbach's alpha for this cultural group on the Rosenberg self-esteem scale is 0.53. Therefore, the reliability of this scale to this cultural group is to be assumed with caution.

6.7. Recommendations

Based on the findings in this study, the following recommendations are made:

- More research studies should be conducted to contribute to a better understanding of people with oculocutaneous albinism.
- Future studies about oculocutaneous albinism should also be conducted in regular schools so that the findings are generalizable.
- A neutral setting (outside the school environment) should be used for future studies to enable participants to be at liberty to express themselves.

- Future research should also concentrate on the development of psychological scales which are suitable for the different cultural groups.
- There should be psychological intervention programmes which include assertiveness training and personal coping skills for learners with oculocutaneous albinism in schools so as to continue to strengthen their self-esteem and assertiveness.
- Support groups for individuals with oculocutaneous albinism should be formed to develop and sustain their self-perception, improve their health prospects and continue to empower them to counter negative attitudes in their communities.
- There should be campaigns through media and outreach programmes in schools and communities with the aim of demystifying and de-stigmatizing the condition.
- Workshops should be conducted with educators in the mainstream schools to assist them in understanding oculocutaneous albinism, its management, and challenges faced by learners with the condition in the schools.

- When designing education policies, policy makers should not only consider the academic, but also the physiological and the psychological needs of learners with oculocutaneous albinism with the aim of protecting their rights.
- Psychological intervention programmes should be accessible to parents of children with oculocutaneous albinism to help them cope with the condition of their children, and thus improving the process of acceptance.

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Appendix 1

English version of the Questionnaire

SECTION A

The following is the questionnaire assessing the level of self-esteem among teenagers. Please be honest about the responds.

1. BIOGRAPHICAL INFORMATION

This part of the questionnaire is about your identifying particulars. Your name and your address are not needed, however, be honest about your age, gender, level of education, and family characteristics.

1.1. Personal information

(a) Age _____

(b) Sex: _____

Female	Male
--------	------

(c) Level of education

Grade 8	
Grade 9	
Grade 10	
Grade 11	
Grade 12	

(d) I have albinism

Yes	No
-----	----

1.2. Family characteristics

(a) My parents are :

Single	
Married	
Divorced	
Deceased	

(b) Number of siblings with albinism:

None	
One	
Two	
Three and more	

(c) Mother's education:

Primary school level	
Secondary School level	
Post Matric	

(d) Father's education

Primary school level	
Secondary School level	
Post Matric	

(e) Guardian's education:

Primary school level	
Secondary School level	
Post Matric	

SECTION B

2. 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**.

		1. STRONGLY AGREE	2 AGREE	3. DISAGREE	4. STRONGLY DISAGREE
1.	I feel that I'm 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 much to be proud of.	SA	A	D	SD
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

KAROLO YA A

Mo tlase ke diputšišwana mabapi le maikutlo a gago.

O kgopelwa go tshepagala ge go araba hle.

1. TŠA BOPHELO BJA GAGO KA KAKARETŠO

Ye ke karolo ya go botšiša mabapi le tša bopelo bja gago ka kakaretšo. Leina la gago le aterese ya gago ya madulo ga di botlhokwa, eupša o kgopelwa go tshepagala go dipotšišo tšeo di botšišwago mabapi le mengwaga, bong, mphato wa sekolo le tša lapa leno.

1.2. Tsebo ka bowena

(a) Mengwaga ya gago _____

(b) Bong: _____

Mosetsana	Mošimane
-----------	----------

(c) Mphato wa sekolo

Mphato wa 8	
Mphato wa 9	
Mphato wa 10	
Mphato wa 11	
Mphato wa12	

d) Ke nale bohwehle

Ee	Aowa
----	------

1.2. Tsebo ka lapa la gešo

(a) Batswadi ba ka:

Ga se ba nyalane	
Ba nyalane	
Ba hlalane	
Ba thlokofetše	

(b) Bana bešo ba go ba le bohwehle ke:

Ga go yo a na lego bohwehle	
O tee	
Ba babedi	
Babararo le go feta	

(c) Mma o feleleditše dithuto tša gagwe:

Sekolong sa phoraemare	
Sekolong sa sekontare	
Ka godingwana ga mphato wa lesome pedi	

(d) Tate o feleleditše dithuto tša gagwe:

Sekolong sa phoraemare	
Sekolong sa sekontare	
Ka godingwana ga mphato wa lesome pedi	

(e) Mothlokamedi waka o feleleditše dithuto tša gagwe:

Sekolong sa phoraemare	
Sekolong sa sekontare	
Ka godingwana ga mphato wa lesome pedi	

KAROLO YA B

ELA TLHOKO DITEMOŠO TŠEO DI LATELAGO:

Mo tlase ke mafokwana a mmalwa mabapi le maikutlo a gago.

O kgopelwa go thala nkgokolo ka gare ga lešakana leo le go tlhaološago bokaone.

- Ge o **dumelelana kudu** le lefokwana leo, gona o kgopelwa go thala nkgokolo fao go ngwadilwego DK (dumelelana kudu).
- Ge o **dumelelana** le lefoko leo, gona thala nkgokolo fao go ngwadilego D (dumela).
- Ge o **ganetšana kudu** le lefokwana leo, gona thala nkgokolo fao go nwadilego GK (ganetšana kudu).
- Ge o **ganetšana** le lefokwana leo, gona thala nkgolo fao go nwadilego G (ganetšana).

	1 Dumelelana kudu	2 Dumela	4 Ganetšana kudu	5 Ganatšana
1. Ke ikwa o kare ke motho wa maemo, ebile ke ipona ke tshwana le batho ba bangwe.	DK	D	GK	G
2. Ke ikwa gore ke nale dika tše di botse.	DK	D	GK	G
3. Ka kakaretšo ke ikwa o kare ke motho yo a palelwago.	DK	D	GK	G
4. Ke kgona go dira dilo tšeo batho babangwe ba di dirago.	DK	D	GK	G
5. Ke ipona o kare ga gona seo nkago ikgantšhago ka sona.	DK	D	GK	G
6. Ke ipona ke le yo a tšwelelago.	DK	D	GK	G
7. Ka kakaretšo, ke kgotsofatša ke ka fao ke lego ka gona.	DK	D	GK	G
8. Ke duma o kare nkabe nka kgona go itlhompha go feta fa.	DK	D	GK	G
9. Ka matšatši a mangwe, ke ikwa o kare ke lefeela la mafeela.	DK	D	GK	G
10. Ka nako ye nngwe, ke ikwa o kare ga go na seo ke se kgonago.	DK	D	GK	G

Appendix 2

INTERVIEW SCHEDULE FOR THE FOCUS GROUP DISCUSSION

Teenagers with oculocutaneous albinism in Polokwane: Their self-esteem and perceptions of societal attitudes

SECTION A

Personal information

(d) Age _____

(e) Sex: _____

Female	Male
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(f) Level of education

Grade 8	
Grade 9	
Grade 10	

Grade 11	
Grade 12	

SECTION B

Societal attitudes and self-esteem

- Briefly describe the attitudes of your community members towards you as a teenager with oculocutaneous albinism.
- Briefly describe the attitudes of your peers towards you as a teenager with oculocutaneous albinism.
- Briefly describe the attitudes of your teachers towards you as a learner with oculocutaneous albinism.
- Briefly describe the attitudes of your family towards you as a person with oculocutaneous albinism.

Appendix 3

Teenagers with oculocutaneous albinism in Polokwane: Their self-esteem and perceptions of societal attitudes

Project Leader: Selepe D.M.

CONSENT FORM

I _____ hereby voluntarily consent to let my child/ children to participate in the following project:

TEENAGERS WITH OCULOCUTANEOUS ALBINISM IN POLOKWANE: THEIR SELF-ESTEEM AND PERCEPTIONS OF SOCIETAL ATTITUDES

I realize that:

1. The study deals with the exploration of the self-esteem of teenagers with oculocutaneous albinism and their perceptions of societal attitudes.
2. The procedure or treatment envisaged might hold some risk for my child that cannot be seen at this stage.
3. The Ethics Committee has approved that the individuals may be approached to participate in the study.
4. The experimental protocol, i.e. the extent, aims and methods of research, has been explained to me.
5. The protocol sets out the risks that can be reasonably expected as well as possible discomfort for persons participating in the research, an explanation of the

anticipated advantages for my child or others are reasonably expected from the research and alternative procedures that may be to his/her advantage.

6. I will be informed of any new information that may become available during the research that may influence willingness of my child to continue in participation.
7. Access to the records that pertain to my child's participation in the study will be restricted to persons directly involved in the research.
8. Any questions that I may have regarding the research, or related matters, will be appropriately responded to by the research leader.
9. Participation in this research is voluntary and my child can withdraw his/her participation at any stage.
10. If any medical problem is identified at any stage during the research, or when my child is vetted for participation, such condition will be discussed with me (parent/guardian) in confidence by a qualified person and/or she/he will be referred to my doctor.
11. I indemnify the University of Limpopo and all persons involved with the above project from any liability that may arise from my child's participation in the above project or that may be related to it, for whatever reasons, including negligence on the part of the mentioned persons.

Signature of the parent/guardian

Signature of the witness

Signature of person that informed the parent/guardian

Signed at _____ this _____ day of _____ 200_____