STARK WHITE: EXPERIENCES OF LEARNERS WITH ALBINISM (LWA) IN PRIMARY AND SECONDARY SCHOOLS IN THE UMLAZI DISTRICT.

by

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DECLARATION

I declare that STARK WHITE: EXPERIENCES OF LEARNERS WITH ALBINISM (LWA) IN SECONDARY SCHOOLS IN THE UMLAZI DISTRICT is my own work and that all the sources that I have used or quoted have been indicated and acknowledged by means of complete references. This work has not been submitted before for any other degree at any other institution.

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ABSTRACT

This qualitative study had a dual purpose. The first was to investigate the experiences of learners with albinism in their school environment and the second was to identify ways learners with albinism navigate those experiences. The study consisted of six secondary school learners in different schools under Umlazi District. One of these schools was a special school that enrolled learners with different learning difficulties, learners with albinism were about 25% of the whole school enrolment. These learners met the sampling criteria of having oculocutaneous albinism, thus having a first-hand experience of the condition.

A review of literature indicated that the poor scholastic achievement of learners with albinism is caused by their poor eyesight, teachers' and learners' bad attitudes toward learners with albinism, and unsupportive family members. Data elicited in this study revealed that learners with albinism in the Umlazi District develop navigation strategies to help them through their discriminatory and prejudistic experiences.

Data was collected using in-depth interviews and focus group discussion. The researcher had specific guidelines in place for participants' health and psychological needs since some of the interview questions touched sensitive issues. Data analysis adhered to the guidelines outlined by Braun and Clark (2006). The interviews were audio-taped and transcribed for data analysis. The researcher listened to audio tapes several times before transcribing them. Data was broken down and classified into six phases that were interrelated. After familiarisation with data the researcher generated codes, searched and identified themes and produced a report.

Participants of this study were teenagers. Teenagers value their privacy, the researcher was aware she was invading that privacy during the interviews. The researcher assured the participants of anonymity and also that data collected will be treated with confidentiality.

Stigma theory provided a framework for understanding variables influencing the experiences of learners with albinism.

From this study several recommendations were made to assist teachers include learners with albinism in their classrooms. The researcher believes the recommendations that emanated from this study will help diminish the school dropout rate of learners with albinism.

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NGIYABONGA KAKHULU, ENIKWENZE KIMINA NIZE NIKUPHINDE NAKWABANYE.

(Translation- Thank you so much, what you did for me, I wish you could do for others too.)

DEDICATION

- To my two angels I miscarried during the period of this study.
- To all the learners and persons with albinism who have experienced discrimination of any magnitude.
- To all the teachers out there who go out of their ways to include learners with albinism and learners with other different learning difficulties in their classrooms.

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CHAPTER ONE

INTRODUCTION

1.1 General introduction

Barriers to learning can be allocated within the learner, within the education system, and within the broader social, economic and political context. Hugo, Nel and Nel (2012) referred to these barriers as intrinsic and extrinsic. Further Hugo *et al.* (2012) stated that the diversity of learners experiencing these learning barriers require teachers who have the knowledge and skills to identify, assess and support them within a classroom in collaboration with other role players. Albinism is one of the intrinsic barriers which manifest itself in various ways in our classrooms. The National Organisation for Albinism and Hypo-pigmentation - NOAH (2010, p. 1) - points out that 'people with albinism always have vision problems that are not correctable with eye glasses and many have low vision'**.**

Like any other human being, individuals with albinism accept themselves to the extent that they are accepted by others; their self-esteem is closely related to the approval of others (Konarska, 2005). Negative attitudes of others can be a significant barrier to learning and general well-being of learners with albinism (LWA). This happens when other learners and teachers stigmatise and treat LWA as imbeciles. NOAH (2010, p.2) argues that albinism does not affect brain development, and many albinos can live highly functional, normal lifestyles. Landsberg (as cited in Lansberg, Kruger & Nel, 2005), confirms this by saying the tendency of stereotyping albinos and other people with visual impairments by assuming that because they are visually impaired they are intellectually impaired as well, should be negated. People, moreover teachers, should liberate their minds from this mentality because their own mindsets may become a barrier to the learning and development of LWA.

Myths around albinism also play a significant role in poor self-esteem and social incompetence in LWA. Teasing and name calling because of the different colour of their skins by other children and community members causes the LWA to hate school. Lund and Lynch (2012) identified young people with albinism who were not attending school, or if they started attending, had dropped out. Reasons included a lack of adaptation of the educational system to take into account their visual impairment, bullying and rejection by peers and lack of parental support.

LWA, because of their low vision, are liable to reach developmental milestones differently from other learners because they lack complete sensory input and restricted interactions with the environment. This also poses an impact on concept development. This can later affect the learners’ ability to infer, comprehend, predict and create during learning activities (Bardin & Lewis, 2008). This includes concepts such as long/short, spatial awareness, and quantity estimation, most of which are the basis of mathematics. Without support structures at school or adequate strategies to face these challenges LWA most probably lose schooling interest.

Several studies have been conducted around the condition of albinism in Zimbabwe and Malawi but very few have been conducted in South Africa. This study will look particularly at the learners’ quality of school life while investigating their experiences and ways they navigate those experiences.

1.2 Purpose of the study

The purpose of the study was to explore the experiences of learners with albinism in primary and secondary schools.

1.3 Rationale of the study

The researcher has chosen this study because of personal interest in learners with albinism due to two reasons. A grade two LWA who was enrolled in the researcher’s mainstream school went to athletics competitions in support of his school mates. Teachers that were with him, out of ignorance, said nothing to the boy as he was running around on a hot day in February. The following day the school received the news that the boy was hospitalized, severely burnt by the sun. The researcher, with her degree in special needs education, felt guilty for not ensuring that teachers took care of the LWA and that the boy should be advised and supervised to stay in the shade. She took a decision to research about other different experiences that LWA face in their schools with the aim of equipping other teachers on how to assist LWA in their schools. Also in the researcher's twelve years of teaching, three LWA have been in the researcher's primary school classroom but it is saddening that none of them finished high school. This also raised questions within the researcher whether teachers' ignorance or negligence was the cause for the high dropout rate, truancy, low self-esteem and poor scholastic performance of LWA.

Discrimination is believed to be one of the key manifestations of stigmatisation. The Save the Children Research Report (2001), states that stigma and discrimination have a damaging impact on the dignity and self-respect of the person being stigmatised. However, concern about how best LWA would like to be understood and treated in the school environment has not yet been sufficiently investigated. With the lack of adequate data, the researcher found it appropriate to investigate experiences of LWA in their schools and through their voices identify ways LWA navigate those experiences.

Since albinism is a rare condition, not many studies have been conducted on this topic. The few studies and literature on the topic of albinism often make the assumption that people with albinism have a poor quality of life because of their disabilities and are exposed to a great deal of discrimination and stigmatisation. This study could, therefore, understand why LWA are underperforming and most commonly drop out of school. Through their narrated experiences the learners still at school will suggest ways of navigating through those experiences.

1.4 The objectives of the study

i. Investigate experiences of learners with albinism at primary and secondary schools.
ii. Identify ways learners with albinism navigate those experiences.
iii. Recommend different strategies to enhance scholastic inclusion of LWA.

1.5 Research questions

i. What are experiences of learners with albinism in schools?
ii. How do learners with albinism navigate those experiences?
iii. What can be recommended to enhance the scholastic inclusion of LWA?

1.6 Significance of the study

This study will be of great significance and assistance to the Department of Education on teacher development as far as inclusion in mainstream schools is concerned as the navigation strategies and recommendations will be a good reference in their classrooms with LWA. Moreover it will equip LWA with skills and strategies to face and overcome challenges that other LWA in the study have strategically overcome and as a result improve their self-esteem.

1.7 Conclusion and overview of the thesis

This chapter provided an overview of the entire study. It presented the background of challenges persons with albinism in general encounter in their daily lives and also challenges LWA face in schools. The purposes of this study together with the core objectives of this study were presented. The researcher further included the set of reasons why she embarked on this particular study and finally the significance of this study was stated.

Chapter two comprises of the literature review on challenges LWA face in schools by providing a definition of albinism, its origin and prevalence. Discrimination and stigmatisation of persons with albinism while referring to the South African constitution are addressed. The chapter also presents literature on challenges brought about by myths around albinism, teachers' and learners' attitudes, and incorporates the theoretical framework to be used in data analysis.

Chapter three discusses methodology used in gathering data. It describes the choice of participants, the instruments used to generate data and a discussion of how data was analysed.

Chapter four presents the data analysis in terms of themes that were identified using vignettes in participants' own words.

Chapter five focuses on theorising about the data and the main findings of the study. It also explores how LWA faced challenging experiences that were brought by the condition of albinism in their schools and how they navigated those experiences.

The next chapter will review relevant literature on albinism and explore the theoretical framework for data analysis.

CHAPTER TWO

LITERATURE REVIEW AND THEORETICAL FRAMEWORK

2.1 Introduction

In this chapter, literature relevant to albinism as a condition and its implications for secondary school learners is discussed. This literature review will serve to unravel data on LWA in their school settings because albinism is a condition that may become a barrier to the learning and development of LWA. This chapter further explores the theoretical framework that is destined to assist the researcher in theoretical analyses of data received from the participants of this study.

2.2 Purpose of literature review

Boote and Beile (2005) stated that a literature review is an evaluative report of studies found in the literature related to a selected area. Apart from giving a theoretical basis of the research and justifying the research, a literature review describes, summarises, evaluates and clarifies the related literature.

Literature can be reviewed in distinct forms but the basic main reason is always the same. Machi and McEvoy (2009) maintained that literature review enables researchers to view the sequencing and growth of knowledge, also it enables the spotting of areas that have not yet been investigated.

2.3 A working definition of albinism

NOAH (2010) defines albinism as an inherited genetic condition that reduces the amount of melanin pigment in the skin, hair and/or eyes. Albinism occurs in all racial and ethnic groups throughout the world. There are several types of albinism but there are two classifications that dominate the field.

2.4 Types of albinism

Albinism is generally classified into oculocutaneous albinism (OCA) and ocular albinism (OA).

2.4.1 Oculocutaneous albinism

Oculocutaneous albinism (OCA) is a type of albinism in which the skin, hair and the eyes lack pigmentation (Oetting, Brillian & King, 1996). OCA is a recessive genetic condition prevalent throughout sub-Saharan Africa. In indigenous Black populations OCA subjects have yellow hair, pale skin that is easily burnt by the sun and blue eyes showing uncontrollable rapid eye movements called nystagmus, photophobia, lack of binocular vision, and poor acuity (Gaigher, Lund & Makuya, 2002).

Oculocutaneous albinism is a condition characterised by deficiency of a pigment called melanin in the skin, hair, and eyes. Oculocutaneous albinism is therefore easily recognisable in dark skinned people due to the lack of pigment (Christianson, Howson & Modell 2006).

2.4.2 Ocular albinism

People with ocular albinism have the same problems in the eye and visual pathways as in oculocutaneous albinism. Those problems include nystagmus, strabismus, photophobia, lack of binocular vision and poor acuity. 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. This may cause the skin and hair of the affected person to appear normal (Oetting, Brillian & King, 1996).

2.5 Origins of albinism

A person inherits one or more defective genes that cause them to be unable to produce the normal amounts of a pigment called melanin. The Newspaper, Nordqvist (2014), in its article on the causes of albinism, stated that several different genes are involved in albinism, depending on the specific type. Researchers have identified several genes that result in albinism.

The genes are located on ‘autosomal’ chromosomes. Autosomes are the chromosomes that contain genes for general body characteristics. Genes carry the information that makes you an individual. We normally have two copies of these chromosomes and genes: one inherited from our father, the other inherited from our mother. Albinism is a ‘recessive trait’ - a person without albinism can carry the albinism trait. Both parents must carry a defective gene to have a child with albinism. When neither parent has albinism but both carry the defective gene, there is a one in four chance that the baby will be born with albinism (Nordqvist, 2014). Little (2011) maintains that albinism is found in 1 out of 1700 people heedless of race or ethnicity.

2.6 Prevalence of albinism

Statistics about the prevalence of albinism is stated by different scholars in Africa and in different countries abroad.

i) Abroad

The prevalence of albinism differs from one country to another. It has been estimated that in the United States of America, 1 person in 17,000 has some type of albinism (Wan, 2003, p. 277), in Norway, 1 in 9650 is affected, and in Northern Ireland, the statistics are 1 in 10 000 (Kromberg & Jenkins, 1982: Mangus, 1992).

ii) In Africa

Studies from Zimbabwe and South Africa, however, show that the prevalence of albinism in these countries is almost 1 in 4,000 (Lund & Gaigher, 2002).

iii) In South Africa

In the 1970 census data for Johannesburg, 206 individuals with albinism were surveyed. Calculations produced a prevalence of 1 in 3900. In terms of ethnicity, the prevalence was lowest among the Xhosa people with 1 in 4 794 and highest in the Southern Sotho population with 1 in 2 041. Albinism’s prevalence among the Swazis was 1 in 2 716 and the Tswanas was 1 in 3481 (Kromberg & Jenkins, 1982).

Venter, Christianson and Hutamo (1995) maintained that high prevalence does not seem to exclusively occur in urban regions. A prevalence of 1 in 1515 was reported from a study of congenital anomalies of live-born neonates in Sovenga, which is a more rural region in Northern-Transvaal. This is higher than the national rate of 1 in 3 900 (Kromberg & Jenkins, 1982).

2.7 Diagnosis of albinism

The presence of eye problems defines the diagnosis of albinism. NOAH (2010) mentions these few points on albinism diagnostic treatment:

- There is no cure for albinism.
- Because albinism is a genetic disorder, treatment is limited.
- Most treatments involve visual rehabilitation.
- Many children will need to wear prescription lenses, which can provide improvements in their vision.
- Children should receive annual examinations by an ophthalmologist.
- Surgery is rarely part of treatment for albinism; however in some cases an ophthalmologist may recommend surgery on optical muscles that minimise nystagmus.
- Surgery can also be done to correct strabismus. While this may make the condition less noticeable, it will not improve vision.
- Children should receive annual skin assessments to screen for skin cancer or lesions that could lead to cancer.

A diagnosis of albinism is suspected when a child develops rhythmic involuntary eye movements within the first few weeks of life and where the eye examination identifies that the light passes through the iris, there is an underdevelopment of the central retina, also the absence of melanin pigment in the eye (Blind Babies Foundation, 1998).

The degree of impairment varies with the different types of albinism. Although people with albinism may be considered legally blind with a corrected visual acuity of 20/200 or worse, most learn to use their vision in a variety of ways and are able to perform innumerable activities such as reading, riding a bike or fishing. Some have sufficient vision to drive a car (NOAH, 2010). Globally debate on whether albinism is a disability or not have started.

2.8 Is albinism a disability?

In the report of the Office of the United Nations High Commission for Human Rights (2013), it is stated that under the Convention on the Rights of Persons with Disabilities, persons with albinism could be considered persons with disabilities. According to article 1 of the Convention, persons with disabilities include those who have long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others.

Some international legislation recognises albinism and associated visual impairments as a disability. The amended version of the Persons with Disabilities Act in Kenya recognises albinism as a disability. Discrimination laws in Australia protect the rights of persons with albinism. In Canada and the United States, persons with albinism are considered “legally blind” and thus as persons with disabilities according to domestic legislation (Office of the United Nations High Commission for Human Rights - OUNHCHR, 2013, p.16). In response to the widespread disappearances and killing of people with albinism in Tanzania, Burundi and other East and Central African countries, the Office of the United Nations High Commission for Human Rights officially declared persons with albinism as disabled (OUNHCHR, 2013).

Dionne Kerr, the executive director of Siyakha Consulting, maintains that persons with albinism are usually as healthy as the rest of the population, with growth and development occurring as normal, but can be classified as disabled because of the associated visual impairments (The Skills Portal, 2011). Similarly Disabled People of South Africa (DPSA) state that albinism per se is also not a disability. It is an inherited condition where a person is unable to produce normal colouring of the skin, hair and eyes. People with albinism have common features such as very light and pale skin, white or sand-coloured hair and very light brown or blue eyes. The absence of pigmentation makes a person with albinism very sensitive to the sun.

The Human Rights Council Advisory Committee (2014) maintains that in South Africa people with albinism are considered as persons with disabilities. Vulnerable groups such as children and refugees have dedicated and consolidated pieces of legislation enacted to protect their rights. However according to The Human Rights Council Advisory Committee (2014, p. 4): ‘the rights of disabled persons are interspersed throughout the South African legal system. The possibility of enacting a comprehensive Disability Act, dedicated to the protection of people with disabilities, has been expressed as the priority, but remains forthcoming for the government. It is preferable that should an Act of this sort be drafted, that it contains a specific section related to albinism, alternatively it should be a dedicated legislation for persons with albinism.’

In South Africa people with disabilities including people with albinism have always been one of the most discriminated against groups. They often suffer unfair discrimination in silence due to societal stigma and stereotypes.

2.9 The South African Constitution and the persons with albinism

There is no Act that specifically addresses issues of persons with albinism. However in the South African Constitution (1996) Section 9 it is stated that:

i) Everyone is equal before the law and has a right to equal protection and benefit of the law.
ii) Equality includes the full enjoyment of all rights and freedoms. To promote the achievement of equality, legislative and other measures designed to protect or advance persons or categories of persons, disadvantaged by unfair discrimination may be taken.
iii) The state may not unfairly discriminate directly or indirectly against anyone on one or more grounds, including race, gender, sex, pregnancy, marital status, ethnic

or social origin, colour or sexual orientation, age, disability, religion, conscience, belief or culture.

iv) No person may unfairly discriminate directly or indirectly against anyone on one or more grounds in terms of subsection (3). National legislation must be enacted to prevent or prohibit unfair discrimination.

v) Discrimination on one or more of the grounds listed in subsection (3) is unfair unless it is established that the discrimination is fair.

In addition, Section 10 of the Constitution enshrines that everyone has inherent dignity and the right to have their dignity respected and protected. Further to this the Promotion of Equality and Prevention of Unfair Discrimination Act 4 of 2000, is a core piece of enabling legislation aimed at facilitating the realisation of the rights of all people in South Africa, particularly minority groups which have been historically marginalised. This would therefore extend to persons with albinism.

2.10 Discrimination against LWA

South Africa is celebrating twenty years of democracy this year, 2014, but discrimination against people with albinism is still evident. People living with the condition of albinism are still facing challenges of stigma, violence, abuse of their rights due to entrenched harmful attitudes and unequal opportunities in education and work (THISABILITY, 2013).

In previous years LWA and other learners with visual impairments were enrolled at a special school but these learners are now enrolled at mainstream schools. Lund (1997, 2001), in her study in Zimbabwe, concluded that LWA can be successfully enrolled in mainstream schools if teachers could cater for their poor eyesight and sensitive skins.

Findings in a study by Pooe-Monyemore (2007) in Gauteng Province, concurs with Gaigher's (2002) findings that the majority of LWA were of the opinion that the problems they experienced at school were more of a social than an educational nature. Lack of social interaction perpetuates the situation of the affected persons, because it means that they cannot access essential services such as health and educational facilities to meet their physical and developmental needs (Pooe-Monyemore, 2007). Dart, Nkanotsang, Chizwe and Kowa

(2010) in their double case study found that both their LWA respondents were performing poorly across all subjects. Not only were they performing poorly at high school but evidently it has been like that even from early ages. In a study by Braathen and Ingstad (2006, p. 7), one of the participants narrated that one of the challenges she faced as she moved to secondary school was the teacher's bad attitude and unwillingness to support her such that she "decided to leave school and get married". Also in a typical case in the North-West Province by Pooe-Monyemore (2007), the rights of a seventeen–year-old learner were tempered with when she was ridiculed and called names by other learners. This resulted in the learner staying away from school.

Thuku (2011) maintains that most women who give birth to children with albinism in Africa fear discrimination for their children and prejudice against them because of the myths and misconceptions surrounding albinism.

2.11 Myths about albinism

Myths around albinism affect LWA and people with albinism in general, all their lives. Some harm them psychologically while others harm them physically. During the two-day conference on albinism in the Gauteng Province, the minister for Women, Children and People with Disabilities, Lulu Xingwana said that South Africans need to do something about changing the mindsets of people who believe in myths and harmful cultural practices that are discriminatory and undermine the dignity of people with albinism (SA News, 2013). People in some parts of Africa as a continent still believe that albinism is a curse or punishment by God or fore-fathers for the wrongs that the parents have done. King, Summers, Haefemeyer and Leroy (2005) maintained that some professional bodies recommended abortions to mothers who gave birth to children with albinism as they believed they would live a difficult life.

Some of the myths are physically and life-threatening to people with albinism. These include: the sacrifice of a person with albinism calms the angry "gods of the mountains" when the volcano erupts; pulling out the hair of a person with albinism brings good luck; and fishermen weave the hair of a person with albinism into their nets to help them catch more fish (Office of the United Nations High Commissioner for Human Rights, 2013). Myths in

South Africa mainly revolve around birth, life and death. Thuku (2011) collected these myths and facts on albinism.

- Myth: That the mother slept with a white man.
  Fact: This is not true. Children born with albinism may look ‘white’ due to absent or reduced pigmentation but are not products of cross race relationships.
- Myth: That a child born with albinism is conceived when a woman has intercourse while she is menstruating.
  Fact: This is biologically impossible.
- Myth: That albinism occurs for people who fail to eat salt.
  Fact: Albinism is a genetic condition and has nothing to do with salt.
- Myth: That albinism is a punishment or a curse from the gods or ancestral spirits due to wrongs done in the family.
  Fact: Albinism is a genetic condition that is passed on from parents to children. Many people are carriers of this recessive gene. Albinism is not a curse.
- Myth: Persons with albinism cannot see during the day but see well at night.
  Fact: Persons with albinism have visual impairments due to lack of melanin pigmentation in the retina. They can see during the day and also at night although they may either be short or long sighted and may need sight aids.
- Myth: That people living with albinism are blind.
  Fact: Persons living with albinism are not necessarily blind but all forms of albinism are associated with some form of vision impairment. However they have enough vision to carry out daily living activities albeit with a variety of challenges.
- Myth: That body parts of persons living with albinism make potent charms that can make people rich and successful.
  Fact: This is absolutely not true. It is a myth spread by witchdoctors in order to enrich themselves at the expense of others.
- Myth: That drinking the blood of a person with albinism gives extra magical powers.
  Fact: This is not true. Persons with albinism are just human beings like anyone else and do not possess any magical powers.
- Myth: That having sex with a person with albinism can cure HIV/AIDS.
  Fact: This is not true. Persons with albinism do not possess any healing powers and any ritual rape or unprotected sex with them will only lead to further HIV/AIDS infections.

- Myth: That albinism is a contagious condition.
  Fact: Albinism is a genetic condition and is not contagious even with blood transfusion.
- Myth: That a person with albinism cannot have normal pigmented children.
  Fact: A person with albinism can give birth to normally pigmented children if his/her partner is not a carrier of a similar recessive gene for albinism. The children may be carriers of the recessive gene but it will not be expressed in them.
- Myth: That persons with albinism are sterile.
  Fact: This is not true. Persons with albinism are fertile and can have children like other people.
- Myth: That persons with albinism don't die, they simply vanish.
  Fact: Persons with albinism die like all other normally pigmented people.
- Myth: That persons with albinism are only found within people of black race.
  Fact: This is not true as albinism is found in all races. However some parts of Africa seem to have higher prevalence rates than other parts of the world.
- Myth: That persons with albinism normally have a short lifespan.
  Fact: This is not true. If enough medical care is given to protect the skin from ultra violet rays of the sun, a person with albinism can attain a normal and productive lifespan.
- Myth: That persons with albinism are mentally retarded and are not intelligent.
  Fact: This is not true. Persons with albinism are intelligent and gifted in many different ways. They also perform well academically like other normally pigmented persons. There are teachers, lawyers, politicians and musicians who are living with albinism. However many persons with albinism in Africa do not realise their potential due to discrimination in the education systems.
- Myth: Children born with albinism are products of incest.
  Fact: This is not true. The parents just happen to carry recessive genes for albinism which become expressed in the children. There are many people with recessive genes but they are pigmented.

Waugh (2005) believes that the television and radio dramas play a big role in perpetuating myths about albinism. People with albinism play characters that portray ghostly supernatural powers. This further leads the public to believe these misconceptions about albinism.LWA, especially teenagers, are largely affected by these myths and misconceptions. Burstal (2012), born with oculocutaneous albinism, maintains that as she became a teenager she became more self-conscious and developed an eating disorder which she believed was linked to her condition and lack of self-esteem. Baker, Lund, Nyathi and Taylor (2010) feel that such beliefs do not only affect LWA academically but also affect their access to employment and marriage. They further concluded that their study demonstrated that good or bad attitudes of friends, family and professionals have an enormous impact on the life experiences of LWA and people with albinism in general.

2.12 Attitudes to LWA

Peoples' mental attitudes generally evaluate everything including other people and concepts. Those mental orientations are then called values (Spooncer, 1992). Attitude theorists have generally accepted the assumption of an interrelatedness of cognitive, behavioural and affective aspects (Eagly & Chaiken, 1993). This assumption concord with the triangular component structure by Spooncer (1992) of attitudes and how individuals respond to stimuli on behaviour, beliefs and feelings.

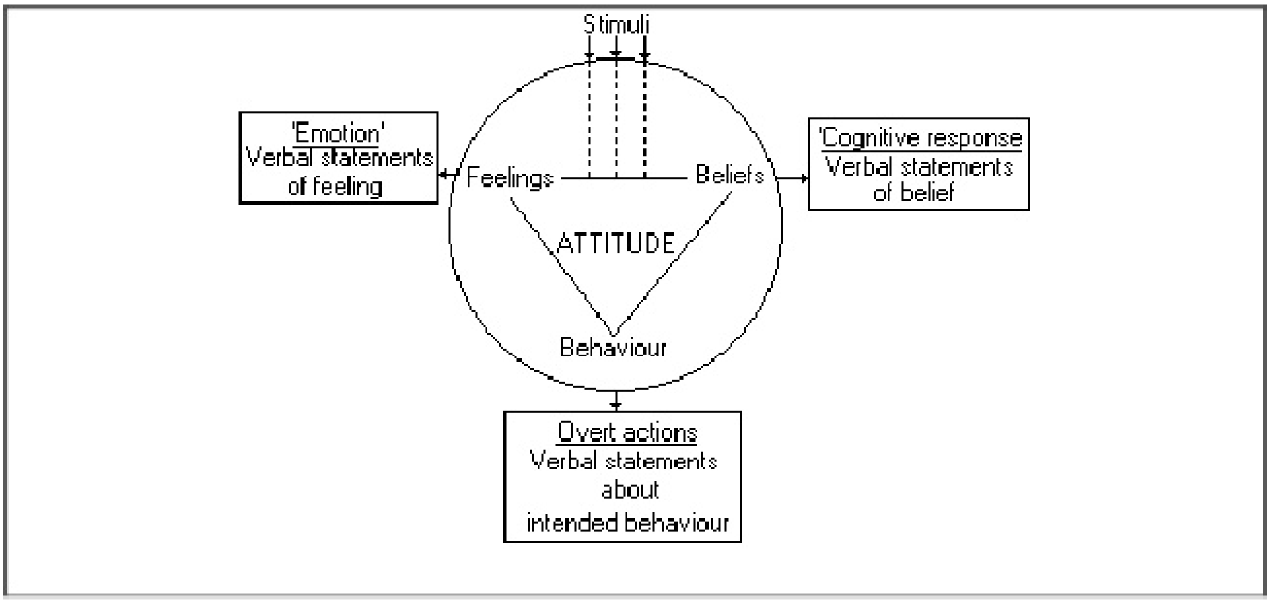

Figure 1: The tripartite component model of attitudes by Spooncer (1992).

According to Baron and Byrne (1997), attitudes involve people's feelings, thoughts and behaviour towards an object. Attitudes towards other people are acquired through experience and are therefore learned.

2.12.1 Attitudes of peers

Selepe (2007), in her study of teenagers with albinism, notes that one of the challenges LWA experience in schools is name-calling. People used to name things so as to control them. NOAH (2005) further highlights that another reason for name-calling, teasing and being insensitive towards LWA is the lack of knowledge, curiosity, desire to learn and inability to pose questions constructively. Different derogatory names in different countries are given to learners with albinism by their peers in schools. In Canada, Wan (2003) mentions that LWA were called 'Whitey', 'Powder', 'Ghost' and 'Casper'. In Malawi, Braathen and Ingstad (2006) found that LWA are called 'Mzungu' - white man, 'Zigoma' - name of the famous gospel singer with albinism, and 'Napwere'- a very wrinkly light brown pea. In South Africa, Ngidi (2005) remembers that he endured names like 'inkawu yasendlini'- house monkey, 'isishawa'- the punished one, 'umlungu'- white man, 'isphiwo'- gift, 'cebile'- wealthy, and 'ilawu'- light-skinned person.

Lund (2001) mentions that learners become cruel to other learners only because they are different to them. This difference could be because of scholastic achievement, skin colour, race or religion. LWA in Lund's study were not only subjected to name-calling but were also ridiculed and beaten by fellow learners. Other learners without albinism avoided them and could not sit, eat or play with them. This form of discrimination appeared to be the most painful and unforgettable experience for these LWA, especially teenagers who are looking for group interaction and acceptance (Kromberg, Zwane & Jenkins, 1987).

Contrary to discriminatory and stereotypical experiences of these LWA, Dart, Nkanotsang, Chizwe and Kowa (2010), in their double case study of albinism in a Botswana junior secondary school, maintain that LWA in that school enjoyed schooling as they had friends who assisted them with school work and even accompanied them home after school. Dart, Lund and Massah (2013) had a similar finding in their study of pupils with albinism in Malawi where LWA were supported by other learners without the condition in their classrooms. One learner mentioned that his classmates offered to write notes for him if he failed to see the board, read what was on the board for him, and lent him their notebooks to copy notes at home.

2.12.2 Attitudes of teachers

South Africa has few special schools that provide individualised educational programs for LWA (Lund & Gaigher, 2002). These schools have buildings that were specifically designed for learners with poor eyesight; they are adapted to reduce glare with shutters on the windows at one side, and a covered walkway on the other. Rooms are equipped with mobile blackboards on wheels which can be moved around to the best position at different times of the day. During the lessons, these learners are allowed to move to the board to better see what is written. All these measures help to reduce poor vision and extreme sensitivity to sunlight. The schools also support and encourage a positive attitude towards albinism and enhance the learner's self-image and self-worth (Lund & Gaigher, 2002).

Teacher support to LWA makes a huge contribution to scholastic achievement. According to Dart *et al.* (2010), LWA perform poorly across a range of subjects. This does not start later in their school lives but evidently so even in primary schools. In their study there appeared to be a lack of understanding from the teaching staff at the schools of the problems that LWA were facing, and lack of recognition of the efforts that they were making in school. They were also concerned about the finding that very few teachers in this school were aware of the problems that the LWA were facing. The teacher who studied special education did not even attempt simple interventions like encouraging the LWA to sit closer to the board. Musiwa (1998) mentions that unsympathetic teachers often order these poor sighted learners to sit down if they happen to stand up in order to move near the board.

Some teachers permit LWA to change their sitting position to best suit their visual capacity. In some instances these learners are given textbooks to use alone while other learners without albinism share (Lund, 1997).

2.13 The rigid curriculum

In the Education White Paper 6 (2001, p. 19) it is stated that “one of the most serious barriers to learning and development can be found within the curriculum itself and relates primarily to its inflexible nature.” The curriculum comes with the content to be taught, methods and procedures to be followed in teaching and assessment, time allocation, and learning materials to be used. This does not leave much space for flexibility.

2.14 Skin sensitivity

Gaigher, Lund and Makuya (2002) are of the opinion that LWA are isolated from activities that stimulate cognitive and perceptual motor development because they cannot take part in outdoor sports and other extra-mural activities due to their poor eyesight and highly sensitive skin. Above the challenges these LWA face in schools, LWA who have “skin type 1(extremely sensitive) living in Durban respectively are likely to experience sunburn at least one day per year,” (Wright, Coetzee & Ncongwane, 2011, p. 2). KwaZulu-Natal (KZN) is a tropical province of South Africa; the sun poses a threat to people with albinism. This threat is worsened by cases where unaffordability of sunscreen lotion prevails. In most cases primary schools are situated far from secondary schools and in summer learners walk these long distances under the burning sun with only their hats to protect them. Pooe-Monyemore (2007) maintains that under the tropical sunshine, their melanin deficient skins develop wrinkles, lentigines, actinic keratosis, and epithelomata from which they may die early in adult life or in middle age.

2.15 The school buildings structure

Most of the schools have steps. According to the National Commission on Special Needs in Education and Training and the National Committee for Education Support Services(NCSNET/NCESS) (1997), there is a challenge of many schools being inaccessible to learners with disabilities. A LWA could be injured walking down the steps especially on a sunny day where vision is more blurred. Some schools have upper levelled classrooms, and the LWA will take more time climbing the stairs for the following period, and at times one can find that rails are not even installed for staircase guidance. More of their problems become intense inside their classrooms.

2.16 The LWA in the classroom

Apart from the general challenges LWA are faced with in schools, more specific problems arise in the classroom.

- Contrast

According to Carney, Engbretson, Scammell and Sheppard (2003), the books supplied to schools are of a normal font and this poses a reading difficulty to a LWA and results in poor reading and writing skills. Every Child Ministries (2008) stipulated that colour contrast is even more helpful than the enlarged font. It was further said that frequently washing the chalkboard with water and using soft coloured chalks is more beneficial to LWA.

- Light

NOAH (2010) maintained that the seating position of the LWA could cause poor learning attainment if the learner is seated in a position where it is easy for the light that is entering through classroom windows to shine directly on the learner. State wide Vision Resource Centre (2012) suggests that light and glare should be controlled in the classroom that has LWA during school hours and if light cannot be controlled by means of blinds or such form, LWA can be allowed to use a set darker corner inside the classroom.

- Concept development

A concept is a mental representation, image or idea of what something should be (Carney *et al.*, 2003). The LWA, because of poor vision, needs assistance making a connection between vocabulary and real objects, body movements and abstract ideas. This learner mostly misses a lot of incidental learning available through vision and consequently develops inaccurate concepts.

Bardin and Lewis (2008) maintained that LWA, because of their poor vision, are liable to reach developmental milestones differently from other learners because they lack complete sensory input and restricted interactions with the environment, which also poses an impact on concept development. This can later affect the learners’ ability to infer, comprehend, predict and create during learning activities (Bardin & Lewis, 2008). This includes concepts such as long/short, spatial awareness, and quantity estimation which are mostly the basis of mathematics.

- Assessment tasks and succession

Some tasks can be highly difficult for LWA and they find it difficult to keep up with the pace of other learners in class. The progression report ends up reflecting the incompetency of the learner instead of knowledge of the subject content. Homework adds to the fatigue of the school day, therefore learners’ work will constantly be of lesser quality (Carney *et al.*, 2003). Ignorance and inconsideration of teachers about these problems could have led to incorrect assumptions about the intelligence of these learners.

In the researcher’s experience with LWA, teachers and learners attitudes especially in the primary school are truly discriminatory, stigmatising and inconsiderate. The researcher can reflect on instances where she was accused by both teachers and learners of favouritism if for instance the researcher takes the LWA to the shaded area during morning assemblies on a very hot summer mornings. Literature reviewed reflects terrible experiences that learners with albinism go through especially at a young age. Comfort that children with albinism find is only available amongst their family members, this could be caused by the natural affection or the counselling sessions that mothers who give birth receive from the hospital. According to Baker *et al.* (2010) when the child with albinism is born in South African hospitals and clinics, the genetic nurse talks to the mother telling her how precious and healthy her baby is and move on to explaining why her baby has a pale skin. This empowers mothers to cope when they take their children back to their communities.

Also a South African born 27year old super model who has the albinism condition told Katy Winter on Daily Mail (2013) online newspaper that it is only recently that she has begun to feel comfortable in her own skin.

2.17 Theoretical framework

In this study the researcher proposed to use the stigma theory by Goffman (1963) to examine and understand experiences of LWA. This theory provides an analytical framework for theorising experiences of LWA looking at discrimination and marginalisation created by categorisations by the ‘normals’ in society.

Goffman (1963, p. 4) defines a stigmatised person as one that possesses “an attribute that is deeply discrediting.” He further mentions three types of stigma:

- “Abominations of the body” that includes different types of physical deformities and conditions such as blindness and deafness.
- “Blemishes of individual character perceived as weak will, unnatural passions, dishonesty.......these being inferred from a known record of mental disorder, unemployment.........and radical political behaviour.”
- “Tribal stigma of race, nation and religion.”

There is substantial evidence regarding the psychological impact of low vision on persons with albinism (Thurston, 2010). People who have sight problems are most likely to experience lack of social support than the general population (Bruce, Harrow & Obolenskaya, 2007). Similar findings are reported for LWA in schools. Students with visual impairment due to albinism are reported to be at risk of social exclusion and of being stigmatised due to the impairment (Hess, 2010). Goffman (1963) maintains that the discrediting social exclusion and disapproval result in a spoiled identity of the stigmatised.

Goffman (1963) refers to those who stigmatise others as ‘normals’ but he does not explain what normality is or how it is constructed. Lund and Gaigher (2002, p. 367), when referring to learners without albinism, say “normally pigmented learners,” suggesting that albinism excludes a person from the ‘normals’. Davis (1997) attempted to explain why the notion of normality is important in trying to understand disability. He states that “the problem is not with the person with the disability; the problem is the way the normalcy is constructed to create the problem for the disabled person” (Davis, 1997, p. 9).

Society creates categorisations, where certain characteristics are considered normal within a category, the outcome can be referred to as social identity. Social identity as Goffman puts it, is based on first appearances, and occurs through mixed contacts where those stigmatised are in contact with the normals (Goffman, 1963). Our anticipation of others, our assumption as to what the person is like, is often based on these first appearances- (Goffman, 1997). Since LWA simply stand out from other learners because of the colour of their skin, other learners are likely to see them as different and not belonging to their category. This reaction makes LWA lose their self-esteem. Dell-Orto and Marinelli (1995) point out that body image and self-concept play an important part in an individual's ability to adjust to a disability. A strong link emerged in a study by Pooe-Monyemore (2007) between self-concept, body image and self-esteem.

Goffman (1963) further distinguishes between the discredited and the discreditable. The discredited are those stigmatised individuals who assume that their 'differentness' is known about or is readily apparent to others. The discreditable on the other hand are attributes that are not readily apparent and therefore, stigmatisation may not result. The management of undisclosed discrediting information about oneself is what Goffman refers to as 'passing' (Goffman, 1963, p. 42). 'Because of the rewards in being considered normal, almost all persons who are in a position to pass will do so on some occasion by intent' (Goffman, 1963, p. 74). Panchankis (2007) argues that those who conceal their stigmatised condition significantly suffer from fear of their secret being revealed.

Goffman contends that 'visibility' of a particular stigma is a 'crucial factor' when determining whether an individual is to be stigmatised against or not (Goffman, 1963, p.48). Attributes such as skin colour and particular physical impairment provide visible evidence of stigma, so their barrier can be immediately discredited. Albinism is unlike other discredited traits that Goffman says can be 'covered' and 'concealed' (Goffman, 1963, p. 102). People with albinism cannot cover their whole bodies to 'cover' this condition so that they will not be easily noticed by other 'normals'. In a school situation a LWA may hesitate to read around other learners because the LWA will have to bring it very close to the eyes. Evidently LWA at school can feel double stigmatised because of the colour of their skin and the visual impairment. Both are 'abominations to the body' that raise immediate negative assessment from others.

The year 2013 marked the 50th anniversary of Goffman's publication entitled Stigma: Notes on Management of Spoiled Identity. Different perspectives have been shared on stigma. Phelan, Link and Dovidio (2008), from a psychological perspective, number different functions of stigma. Stigma is used to exploit and dominate people by keeping them down, or to force others into conforming to the norm of the group, or finally for disease avoidance (Phelan *et al.*, 2008).

Bos, Pryor, Reeder and Stutterheim (2013) appreciate Goffman's work on stigma as he discussed examples of stigma due to race and ethnicity, and stigma due to disabilities and moral functions. Within social psychology they discuss stigma and prejudice as two overlapping phenomena. Literature studied marks a remarkable overlap where stigma is viewed to involve reactions to perceived negative deviance while prejudice does not necessarily connote a reaction of deviance.

Stigma related literature distinguishes between four dynamically related manifestations of stigma:

- Public stigma

  It is based on Pryor and Reeder's (2011) conceptual model. It represents people's social and psychological reactions to someone seen to possess a stigmatised condition. Public stigma consists of the cognitive, affective, and behavioural reactions of those who stigmatise. The cognitive representations of a stigmatised condition can evoke emotional and behavioural reactions.

  Four such cognitive representations were identified.

  - The onset controllability for the stigmatised condition.

    High level of the attributed personal responsibility for the onset of the deviant condition erupt anger and stigmatisation behaviour whereas low levels of personal responsibility result in sympathetic feelings and a wish to help (Weiner, Perry & Magnusson, 1988).

  - The perceived severity of the condition.

    High level of perceived severity erupt feelings of anger and sympathy in perceivers and when both these emotions occur, contradicting emotions and peculiar interactions are displayed (Dijker & Koomen, 2003).

- The perceived dangerousness of the condition.

  Perceivers here in fear of danger elicit avoidance (Bos, Kok & Dijker, 2001).

- The perceived norm violation.

  These perceptions are positively related to anger and social exclusion, and are negatively related to sympathy.

Usually people possess both implicit and explicit negative reactions to stigmatised conditions. Implicit reactions involve a reflexive system that result in immediate and automatic responses. On the other hand explicit reactions come from a rule based system that entails controlled and thoughtful responses (Pryor, Reeder, Yeadon & Hesson-McInnis, 2004).

- Self stigma

  It signifies the social and psychological impact of possessing a stigma. Self stigma involves the anxiety of being exposed to stigmatisation and the potential internalisation of the negative beliefs and feelings associated with the stigmatised condition. Public stigma is the source of self stigma as people with the stigmatised condition are aware of the attribution of negative feelings about their condition. Self stigma as public stigma has cognitive, affective, and behavioural characteristics (Mak & Cheung, 2010).

  Herek (2009) maintains that the self can be impacted by public stigma in three ways thus: through enacted stigma which is the negative treatment of the person with the stigmatised condition, through felt stigma which is the experience or prediction of devaluation on the part of a stigmatised person, and through internalised stigma which is the minimisation of self worth together with the psychological anxiety experienced by people with a stigmatised condition.

  Stigmatised people can assume to alleviate the negative psychological and social impacts of stigmatisation by adopting different coping strategies. Pinel (1999) states that stigmatised individuals may disengage from the stress resulting from stigma choosing from two main forms of disengagement which are physical and social avoidance of situations in which stigma may be a threat, and denial or mitigating of prejudice and discrimination.

Miller and Kaiser (2001) maintain that engagement coping can be distinguished by whether it is aimed at acquiring primary or secondary control over a stigmatising situation. Further they explain that primary coping involves changing the stressful situation by controlling the situation or the self in that particular situation whereas secondary coping has to do with adjusting to the stressful situation. Primary control coping entails problem solving, emotion regulation and expression (Clark, Anderson, Clark, & Williams, 1999). Secondary control coping entails cognitive restructuring, distraction, and acceptance (Compas, Connor-Smith, Saltzman, Thomsen, & Wadsworth, 2001).

- Stigma by association

  It is largely linked with Goffman's (1963) stigma theory and involves social and psychological reactions of people associated with a stigmatised person like family and friends. Devaluation by association not only occurs when there is a meaningful connection between the non-stigmatised and the stigmatised person, but can also be based on random choices by the stigmatiser. Research on stigma by association have been found to be eliciting low self esteem and distress to persons who are associated with the stigmatised individuals (Mak & Kwok, 2010). Often people try to convince the stigmatised person to conceal the stigmatising condition (Phelan *et al.*, 1998).

- Structural stigma

  It is understood to be a situation where the society allows and condones the stigmatised status by its institutions and ideological systems (Corrigan & Lam, 2007).

These four manifestations are interrelated but the consensual understanding is that a social attribute is devalued and the public stigma therefore considered to be the core of the other three (Bos *et al.*, 2013).

Goffman’s stigma theory portrays the abhorrence of the body as the cause of stigmatisation by the normals. These stigmatised people are all regarded to be having spoiled identities. Literature reviewed proves this to be true but, seemingly as they grow they psychologically and socially come to terms with their beings and they cope well. A young lady with albinism in a study by Wan (2003) happily publicly revealed her uniqueness and out of the positive responses and attention from the normals she said she enjoys being different from other people.

2.18 Conclusion

Albinism is defined in this chapter as a genetically acquired condition which is largely associated with visual impairments. Origins of this condition, its origins and prevalence in and out of this continent are presented. Different countries including South Africa do see albinism as a disability due to low vision and skin sensitivity of persons with this condition.

LWA are presented by literature reviewed as discriminated and stigmatised individuals by their peers and teachers at schools. The stigma theory is also introduced in this chapter to frame this study and assist the researcher to understand the psychological input stigmatisation has on people with ‘abominations of the body’.

The following chapter will present methodology used in this study.

CHAPTER THREE

METHODOLOGY

3.1 Introduction

The previous chapter presented the literature review and theoretical framework for this study. In this chapter, the researcher's argument for the choices made in the research design for this qualitative study is presented. Participants identified to participate and the data production instruments used for the production of data in this study is also presented. Ethical considerations, issues of validity, reliability and biases are also dealt with. Next, the researcher will introduce the qualitative route this study took and justify this choice of methodology.

3.2 A qualitative study

A qualitative research method was chosen for this study because the researcher wanted to "find out not only what happens but also how it happens and why it happens the way it does" (Henning, 2004, p. 3) in the lives of LWA. According to McMillan and Schumacher (2010) qualitative research is concerned with processes and meanings. Researchers in this field, study things in their natural settings, attempting to make sense of, or interpret phenomena in terms of meanings people bring to them. There is an emphasis on gathering data in real life situations or natural settings (McMillan & Schumacher, 2010). In this study the researcher attempts to make sense of the lives of LWA through their narrated experiences in their schools as Pilot and Beck (2010) maintained that conducting a study qualitatively gives the researcher the opportunity to conduct the study in an in-depth holistic manner by collecting rich narrative materials whilst using an unrigid research design.

This qualitative study also provides an insider knowledge which has become emic. According to Henning (2004) an emic categorisation of knowledge means that the researcher makes notes and then locates knowledge that has been constructed into categories that the researcher builds up inductively from what the researcher has learnt from the participants.

Mothilal (2010) indicates that the issue of voice is important to qualitative research. Qualitative approaches assist us to note different voices and the need to consider whose voice will be presented how, in what way, and for what purpose (Henning, 2004). For participants' voices to be clear, the researcher used verbatim accounts from participants (McMillan & Schumacher, 2010) in data analysis. However, the voice of the researcher is also noted in the interpretation and meaning-making process. It is important that the voices of the participants are not lost in the interpretation and also that the researcher does not bias the study to mean what she wants it to mean (Henning, 2004).

3.3 Locating the study within the research paradigm

'A paradigm is 'a world view and a general perspective on complexities of the real world' (Polit & Beck, 2010, p. 10).Cresswell (2002) takes this further saying that the design of the study begins with the selection of a topic and a paradigm. Paradigms in the human and social sciences help us to understand the phenomena and they advance assumptions about the social world, how science should be conducted and what constitutes legitimate problems, solutions, and criteria (Cresswell, 2002).

This study was concerned with interpretation and understanding of a particular phenomenon which is experiences of LWA in schools, with the aim of generating data. The researcher decided to locate this study qualitatively, specifically in the interpretative paradigm. According to McMillan and Schumacher (2010) in interpretivism, reality is a social construction, meaning that reality is seen as multi-layered, interactive and shared social experience interpreted by individuals. Interpretivism as an epistemology assisted the researcher to collect data in an interactive way with the aim of understanding and interpreting the meaning underlying the behaviour of participants (Denzin & Lincoln, 2005; Merriam, 2009). Confirming this is Henning (2004), who states that epistemology is the philosophy of knowledge or ways used to acquire that knowledge. As humans, we acquire knowledge by enquiring using certain methods.

According to Cohen and Crabtree (2008), interpretivist positions are founded on the theoretical belief that reality is socially constructed and fluid. Thus, what we know is always negotiated within cultures, social settings, and relationships with other people. From this perspective, truth cannot be grounded in an objective reality, what is taken to be true is negotiated and there can be multiple, valid claims to knowledge. The researcher in this study used semi-structured interviews and open-ended questions to produce data to adequately allow an informative dialogue to collaboratively construct a meaningful reality. The epistemology in interpretivism is that knowledge is subjective; truth cannot be grounded in an objective reality (Cohen & Crabtree, 2008).

Angen (2000) offers some criteria for evaluating research from an interpretivist perspective that the researcher adopted for this study:

- careful consideration and articulation of the research question
- carrying out inquiry in a respectful manner
- awareness and articulation of the choices and interpretations the researcher makes during the inquiry process and evidence of taking responsibility for those choices
- a written account that develops persuasive arguments
- evaluation of how widely results are disseminated
- validity is a moral question and must be located in the discourse of the research community.

Mothilal (2010) argues that methodology is concerned with the specific ways and methods that we can use to try and understand our world better. It is important to distinguish between method and methodology. Method shows a way of doing something. According to Cohen, Manion and Morrison (2007), methods refer to a range of approaches used in educational research to gather data which is to be used as a basis for inference, interpretation, explanation, and prediction. Methodology on the other hand focuses on the process and the kind of tools and procedures used to deliver data and findings that will reflect the research question and suit the research purpose (Henning, 2004).

The technique that the researcher used in this study was that of a case study and the method used to generate data was interviews. This is explained further in the sections that follow.

3.4 Case study

Cresswell (2009) describes a case study as comprehensive investigation with a boarded structure which is aimed at obtaining data to give the understanding and make meaning of the situation. The definition of case study is independent of particular procedures negotiated. It is rather dependant on the individual case that the researcher takes interest in exploring (Stake, 2005). It can therefore be argued that case study is not a procedural option but what the researcher intends to explore for better understanding of the particular phenomena under study.

According to Robson (2002) and Hitchcock and Hughes (1995), case studies are likely to share the following characteristics:

- they usually employ multi methods of data collection and analysis
- they involve individuals / actors / organisations in a particular context / setting
- they are empirical in the sense that they collect data to analyse events / phenomena in a particular case
- the presentation of the case tries to capture the richness of detail of the situation

The researcher found these characteristics to be tailor made for this study as they are the bases of why the researcher used this technique for this study.

3.4.1 Justification for case study

In this study, the researcher saw fit to use case study design as the study explores a group of LWA with individual subjective experiences (Cohen *et al.*, 2007). The researcher was intrigued by three ideologies of qualitative research that are connected and sustained by the case study design: telling, perceiving and elucidating (Cohen *et al.*, 2000). These ideologies were highly relevant to this study. Case study design is well aligned with the interpretive paradigm as it also aims at capturing the individual and subjective experiences negotiated by the individuals (Stake, 2005; Yin, 2003).

The case as a ‘unit of analysis’ (Miles & Hubberman, 1994, p.25) in this study is the experiences of LWA at Umlazi District. This case could not be studied without considering its context, their schools and attitudes of teachers and other learners without the condition of albinism. It would have been impossible for the researcher to have a clear understanding of the experiences of these LWA without considering the different contexts that they are taught in, which in this case is mainstream and special schools.

3.5 Data Generation Plan

QUESTIONS	DATA COLLECTION PLAN
WHY is the data being collected?	- To elicit experiences of learners with albinism in a special school. - To explore ways learners with albinism navigate those experiences.
WHAT is the research strategy?	• One-on-one semi-structured interviews. • Focus group semi-structured discussion.
WHO will be sources of data?	Learners with oculocutaneous albinism at Umlazi District.
HOW many of the data sources will be assessed?	Six participants were selected to participate in both semi-structured one-on-one interviews and focus-group semi-structured discussion. Selection was based on their teacher’s assessment of the ability to voice inner-most feelings.
WHERE is the data to be collected?	At the school participants attend.

HOW often will data be collected?	Twice. 1 – One-on-one semi-structured interviews of six LWA and 1 – focus-group semi-structured discussion for six LWA.
HOW will data be generated?	Data was captured during interviews using a voice recorder. Writing down of specific observations was also done soon after the interviews to capture the moments.
JUSTIFICATION for this plan for data generation.	• The design would bring cohesion to the data generating process to answer the questions in the study. • Interviews allowed for open-ended questions so that participants could relate their experiences freely. The researcher was also able to elicit as much data as possible without limiting the participants. • Focus group discussion allowed participants to share their thoughts and experiences in accordance with the questions asked. Detailed information that was required was acquired. • The recordings of the interviews and discussions increased the trustworthiness of the data since the entire participants' oral contributions were captured. • Learners reflected on their individual navigation strategies.

3.6 Selection of participants

Selection of participants for this qualitative study was purposefully done as participants were appropriately selected to best inform the research questions and enhance the understanding of the phenomenon under study (Cresswell, 2009).

3.6.1 Selection and description of research sites

Uthando Special School was selected for this study because it has the highest enrolment of LWA in Umlazi District.The school has an enrolment of 285 learners with different disabilities and 15 of those learners have albinism. The school is situated in the township. This institution was previously a hospital for children with physical disabilities. The floors all around the school are levelled for easy access to all learners especially the ones in wheelchairs. Even watching from a distance, the researcher could deduce that teachers and learners in this school have a good relationship.

The other three schools were selected because they each enrolled one learner with albinism. They also are under Umlazi District in different wards.

3.6.2 Sampling

In this study, the researcher used purposeful sampling to identify information-rich participants who had the ability to answer open-ended questions. The researcher asked for the assistance of the teachers who teach at these schools, who know the learners better, to help select participants who were easy to talk to. Six LWA were therefore hand-picked because they possessed the particular characteristic of having albinism (Cohen *et al.*, 2007).

3.6.3 Sample size

Sandelowski (1995, p.179) maintains that a “common misconception about sampling in qualitative research is that numbers are unimportant in ensuring the adequacy of a sampling strategy.” The researcher in this qualitative study typically involved a small sample size of six LWA.

This study is also gender sensitive as it consists of three girls and three boys, all in the secondary school level of education. Leduc (2009) states that gender sensitive research is not a research on men or women, rather it is a research that pays attention to similarities and differences between men and women’s experiences and view points, and gives equal value to each. Affirming this statement, the Association for the Development of Education in Africa (ADEA) Working Group on Higher Education (2006, p.4) postulates that “integrating a gender perspective into research can improve its relevance, coverage, and quality.”

3.7 Data generation

Data in this study was obtained by interviewing LWA using semi-structured, one-on-one open-ended interview questions to elicit information from the research participants (Overcash, 2004). A focus group discussion was carefully planned and designed to obtain details of experiences (Kruger, 1994) of LWA in a permissive, non-threatening environment. As data was being gathered in this study, care was taken to ensure that the voices of the participants were heard and the researcher did this to ensure that the trustworthiness of the collected data would not be compromised (Golafshani, 2003; Onwuegbuzie & Leech, 2007).Semi structured interviews was the best research strategy used by the researcher in this study to elicit data from the research participants.

- Semi-structured interviews

Interviews in a form of one-on-one semi-structured sessions elicited loads of information for analysis. These one-on-one sessions were framed by open-ended questions that required participants’ responses. The researcher used a voice recorder to audio tape participants’ responses. Recordings were later transcribed for use in data analysis and they assisted the researcher to familiarise herself with the data of the study during theme and categories formulation. Interviews help to understand human behaviour and to add value to the case study. Open-ended-ness of the questions used in the semi-structured interview sessions provided more comprehensive data (Denzin & Lincoln, 2005).

According to Henning (2004), to construct a meaningful reality, there must be a collaborative and comprehensive dialogue between the researcher and participants. The core aim of the semi-structured interviews format is to create a rapport between interviewer and interviewee to comprehend different experiences in interviewees' lives instead of obtaining explanations for some behavioural features in their lives (Denzil & Lincoln, 2005). This aim best suited this study as it aimed to obtain the understanding of different experiences from different participants sharing a similar condition (Denzin& Lincoln, 2005).

Participants answered questions narrating their experiences as LWA in their schools. No time limit was set for the interviews, participants responded freely and the researcher was able to probe for clarity. One question lead to another and more information was gained without limiting the interview. The interviews started as conversations and intensified to more specific questions related to their experiences with albinism. According to Lincoln and Guba (1985) in Cohen, Marrion and Morrison (2007), unstructured interviews are useful when the researcher is aware that she has no personal understanding of a particular phenomenon under study, and therefore relies on participants' narrations for understanding. Cohen *et al*. (2007) maintain that an unstructured interview is the most flexible tool for data collection as it allows for in-depth understanding of a phenomenon studied.

Semi-structured interviews were conducted conveniently at the participants' schools in the comfort of their classrooms and ensuring that the sense of the school situation, which the study was based on, was not lost. All the sessions were arranged in a way that did not interfere with teaching and learning.

- Focus group discussion

Krueger (1994) defines a focus group discussion as a well-planned discussion carefully designed to gain information and experiences of a defined area of interest in a free environment. The researcher facilitates the discussions that occur in a meeting that the researcher convened.

Focus groups in studies dealing with some sensitive issues could be challenging as participants may feel it is causing them to parade their experiences, consequently this feeling may cause participants to withdraw important information for the study. To avoid this situation, the researcher presented a vignette in the form of a radio drama as a projective technique.

- Defining vignettes

Renold (2002) defines vignettes as short dramas or written stories that may also come in pictures which participants, in either a qualitative or quantitative study, may comment upon. It "explores participants' subjective belief systems" (Renold, 2002, p.3). Finch (1987, p.105) similarly defines vignettes as "short stories about hypothetical characters in specified circumstances to whose situation the interviewee is invited to respond."

Braun and Clarke (2013) maintained that vignettes are useful in studying potentially sensitive issues. They further stated that responding to the hypothetical scenario is less threatening than responding to questions personally directed. The issue under study was a very sensitive issue; the researcher found that the use of the radio drama was useful in engaging learners in this study to discuss sensitive issues. The participants who were hesitant to open up in a discussion found it very easy to respond to questions based on the characters in the radio drama. Since the drama was derived from real experiences it encouraged the participants in this study to speak out about experiences of personal abusive forms of behaviours with the knowledge that it had happened to others (Renold, 2002).

- The radio drama – Love Builds

The main character in this radio drama is Madalo who is a nine years old girl with albinism. Madalo is living with her mother Mirriam. In a school that Madalo is enrolled in, she encounters discrimination and prejudice from her peers and her ignorant teacher who misinterpret Madalo's eyesight problems for laziness and poor learning ability. Madalo ends up dropping out of school.

When a new teacher Mr. Zgambo joins the school, things started to change. With his LOVE for all the children and experience with learners who have different learning difficulties, he assists his fellow teachers and Madalo's peers to understand challenges Madalo faces and their causes. This understanding results in Madalo coming back to school and enjoying her school life with the support from the teachers and her peers. LOVE BUILDS.

This radio drama was written by Edgar Nyirenda in Malawi. It resulted from a study by Lynch and Lund (2011) which identified why young people with albinism did not attend school.

3.8 Data analysis

Durrheim (1999) states that data analysis is aimed at converting information into answers. This process in this study was ongoing throughout the research process. Regarding data analysis Merriam (2009, p. 171) maintains that "Data analysis is one of the few facets, perhaps the only facet of doing qualitative research in which there is a preferred way." The preferred way as Merriam (2009) put it is analysing data during the stage of data collection instead of waiting until all data is collected. The researcher followed this preferred way in analysing data from the research participants from the first interview.

Data analysis strategy used by the researcher was carefully considered to make certain that the design was consistent in a sense that analysis matched the type of data, the purposes of the research, and the research paradigm (Durrheim, 1999). The research paradigm for this study was interpretivism which aims at gathering in-depth information. The chosen strategy was undertaken whilst cautiously adhering to ethical regulations set for this study.

3.9 Ethical considerations

Denzin and Lincoln (2005) are of the idea that researchers in qualitative studies are invaders in the participants' lives, therefore they need to have good manners with their codes of ethics adhered to very strictly. Ethics, according to Cohen and Swerdlik (2005), is a shelf of principles for appropriate, right and good conduct. Researchers in case study research invite their participants of their studies to elicit personal information and experiences that could be detrimental to the participants' lives. Participants in the study risk social alienation, ridicule and loss of dignity as they honestly respond to the researchers' questions, therefore it is the duty of the researcher to ensure beyond doubt that ethical regulations are met at all times during and after the research process (Denzin & Lincoln, 2005).

Participants of this study as junior citizens of South Africa are protected by the South African Constitution particularly in the Bill of Rights, which is the cornerstone of democracy in South Africa, where it is enshrined that human dignity, equality and freedom of all South Africans should never be compromised. The researcher respected their rights as South African citizens and again ensured that the study was in line not only with the research ethics but also with Ubuntu ethics. "A person is socialised to think of himself or herself as inextricably bound to others ………… *Ubuntu ethics* can be termed anti-egoistic as it encourages people from seeking their own good without regard for, or to the detriment of, others and the community" (Nkondo, 2007, p.12). The researcher ensured she did not go beyond ethical rules to protect the participants in this study knowing that their relationship was influenced by role, status, language, and cultural norms (Gay *et al.*, 2006).

For more protection of participants, the researcher sent her proposal to the University of KwaZulu-Natal to solicit clearance. The research was fully approved and was given the reference number: 2/4/8/250. During the research process, the researcher developed a caring and empathetic relationship with the participants, under a trusting and non-oppressive environment (Denzin & Lincoln, 1998). To ensure the sustainability of this trust throughout the research, the researcher adopted the contextualised-consequentiality model by House and Smith in Denzin and Lincoln (1998). Three principles that guide this model are "mutual respect, non-coercion and non-manipulation, support of democratic values and institutions, and the belief that every research act implies moral and ethical decisions that are contextual" (Denzin & Lincoln, 1998, p.38).

Principles from the American Psychological Association (APA) Ethics Code in Swenson (2007) were followed in this study:

Beneficence - the results of this study will assist in the understanding of different experiences of LWA; and non-malfeasance - the researcher strived to protect the welfare and rights of the participants;

Fidelity and responsibility which the researcher showed by establishing a trust relationship with the participants;

Integrity - the researcher gave an accurate and truthful depiction of the findings within the study and did not use deception or dishonesty to convince the participants to participate in this study (Elmes, Kantowitz & Roediger, 1999);

Justice - the researcher adhered to this principle by being aware of any biases by the researcher and taking precautions not to let this, as well as her limited expertise, cause the study to be unjust.

Respect for peoples' rights and dignity - Throughout the study the researcher was aware of and respected the differences caused by aspects like ability, culture, age, gender, race, and socio-economic activity. This was important as the LWA differed from the researcher in some of those aspects (Swenson, 2007).

To seal an agreement between the participants and the research, an informed consent was given and signed, anonymity and confidentiality was re-assured.

3.9.1 Informed consent

To participate in the study, participants are required to give their informed consent. In qualitative research the informed consent is highly important because of the personal and in-depth nature of the information to be collected (Duffy, 2008). Swenson (2007) gives a list of guidelines from the APA Ethics Code concerning the contents of the consent form. These are: participants must understand - the purposes of research; the foreseeable consequences of withdrawing from the study; their right to withdraw at any time during the research process; the potential risks; harmful effects due to participation; the benefits and incentives for participation; the limits of confidentiality; and whom to contact should any queries about the research arise. These guidelines are also in line with the code of Professional Ethics as defined in the South African Council for Educators Act (2000) and that of the University of KwaZulu-Natal.

Participants in this study gave consent verbally and on paper to partake in the research. Participants were all minors. Children under the age of eighteen are legal minors in South African Law (1983) and are not fully capable of acting independently without assistance from parents or legal guardians. The researcher asked them to give assent and their parents to give consent by signing the form. Copies of the assent forms were typed using the bigger font to ensure that LWA were able to read what was contained.
Henning *et al.* (2005) stated that the researcher needs to also get consent from the institution head where the research will be conducted. The principals of schools as gate-keepers were also given consent forms to sign as they granted the researcher the permission.

3.9.2 Anonymity and confidentiality

The researcher used pseudonyms and codes to conceal participants' identities. The researcher was also discreet about the names of the schools. Participants all agreed that findings of this study could be published and they were more pleased about this knowing that people, especially ill-mannered teachers and peers, would now possibly change their bad attitudes towards any LWA.

3.10 Conclusion

In this chapter the research paradigm, design and methodology were discussed in detail. The researcher chose a case study method to present the case of the experiences of LWA at Umlazi District. Methods used for sample and data collection, analysis and interpretation were explained and justified. Finally validity and reliability as well as ethical considerations regarding the research process were highlighted. The research findings will be discussed in chapter four.

CHAPTER FOUR

RESEARCH FINDINGS, ANALYSIS AND DISCUSSION

4.1 Introduction

The previous chapter looked at the researcher's justification for the methodology and research design chosen for this study. This study looked at the experiences of six LWA and how they navigate those experiences. The data production instruments used enabled the researcher to elicit in-depth information from the participants. The method of analysis for this study was ongoing throughout the process of data collection. Four themes emerged and in this chapter data collected is discussed in light of related literature and the theoretical framework of a stigma theory that underpinned this study.

4.2 Overview of research themes

THEMES	SUB - THEMES
MEDICAL CONCERNS	• Visual impairment • Headaches • Sunburns
TEACHING AND LEARNING	• Community effects • Learning achievement • Inadequate teacher support • Lack of teacher understanding
DISCRIMINATION AND PREJUDICE	• Segregation • Self-concept • Low self-esteem • No sense of belonging • Physical harm

NAVIGATION STRATEGIES	• Avoiders • Deniers • Dis-identifiers • Accepters • Emotional regulators • Emotional expressers

4.3 Medical concerns

LWA experience pain and suffering like all human kind. However, it is noted in this study that apart from general sufferings that require medical attention, participants typically shared particular health conditions that hamper their school life and life in general. These health conditions included visual impairments, headaches and sunburns.

4.3.1 Visual impairments

Participants mentioned eyesight problems. According to Ashley (1992), visual treatment in people with albinism can improve their vision but nothing can be done to correct the lack of fovea in the retina or to change the routing of the optic nerves through the brain. Eyesight problems affected the participants in different degrees. Only one of the participants admitted that she never had her eyes medically tested. Four of the other five participants that were eye tested were given eye glasses but only one reported that those glasses assisted her with eyesight problems that she mostly encountered in the classroom.

> *Mthandeni: I honestly cannot see what is written on the board. Even if I sit in the front it is the same. Teachers say I have to use glasses but I did, they don't work. I have a lot of teachers who just don't understand.*
>
> *Nontando: I struggle to see a printed document, if the print is too small it looks like spilled ink, when we are writing from the board my eyes get tired…. I had eye tests done and they gave me glasses but they didn't improve my eyesight…*

Luthando said she has never been to a medical practitioner to test her eyes. One of the teachers in her school realised her eyesight problems and bought her reading glasses.

> *Luthando: Yes, I don't see the board properly, I then go stand or sit in the front. I can see what is written on a paper. I never went for eye testing but my teacher bought me glasses, they were not helping me.*

Siyamthanda brought forward the fact that there are other things that make his eyesight problems worse in the classroom.

> *Siyamthanda: Yes, I don't see quite well on the board. I had my eyes tested at the clinic and they recommended glasses for me but they just did not help, the light also affects me, it makes it more difficult for me to see what is written in the board, the light makes the board shine, also when it is hot and other learners start a fan, the reflection of a moving fan on the board makes it even worse.*

Only Athandiwe reported that the eye glasses that the optometrist gave her did improve her eyesight.

> *Athandiwe: My grade 1 teacher Ma'am Mthethwa knew I could not see well, she met my mom and asked her to take me to the doctor, they organised glasses for me…I cannot see what is written on the board because I no longer use my glasses, I accidentally broke them last year. I can read handouts I don't have a problem with that because I can bring the paper close to my eyes.*

Little (2011) stresses the importance of early eye assessment and examination, and also that the assessment should be done by an eye-care professional who can prescribe glasses suitable for that patient. Most of participants' parents were not employed therefore they did not have money to be seen by eye specialists and to pay for suitable eye devices. When glasses participants used seemed not to assist them, they ceased using them which resulted in constant headache attacks.

One other participant gave a heads up to the researcher when she said:

> *Zithande*: *I don't have a problem with my eyesight…I had my eyes tested some time ago and the doctor gave me glasses. I do not need them really, I can see. What I wear is sun glasses on sunny days.*

As the researcher continued interviewing this participant, she began to hear contradicting statements where the very participant said she walks to the board to see what is written and she brings a book close to her eyes to see better. Sunglasses are classy and fashionable; there is a good possibility that Zithande disliked vision glasses because of their thick lenses. According to Overbury, Greig and West (1982), stelescopic spectacles that help see objects at a distance are not used by students with low vision because they consider them unattractive and they make the person wearing them seem different.

4.3.2 Headaches

Headaches are also perceived as one of the factors hampering the participants' smooth access of education. Five participants reported that they suffer from constant headaches.

> *Zithande: I only wore the glasses from the doctor with the hope that they would help with my headaches but they did not.*
>
> *Mthandeni: If there are too many notes to take from the board I stop writing because I always end up with a severe headache. This also happens if I study for a long time.*

The headache attacks that the participants constantly experience evidently affect their reception of education. These attacks, according to the participants, caused them to miss classes and even brought about detrimental consequences in their grades.

> *Luthando: My teacher said the glasses she bought me would help heal the headaches that trouble me and keep me from coming to school.*

> *Siyamthanda: My day was good from the morning then it changed during the day, I was sick suffering from a headache during maths period, it really disturbed me but I did take medication. This headache troubled me almost daily such that when I was in grade six I could not even write my examinations and it caused me to repeat that grade.*

Nontando's parents worried so much about these headaches that troubled their daughter such that when the glasses from the doctor did not help, they began to investigate what other causes there could be for her headaches.

> *Nontando: …glasses only strained my eye muscles and I would end up with a severe headache. The doctor said the glasses would help calm the headache but they did not. My parents think the headache is caused by the cultural ritual that they need to perform for me.*

Little (2011) maintains that headache discomfort or fatigue in people with albinism is caused mostly by physical response to light not just stress and anxiety. People with albinism squint their eyes and peer to see. Lund and Gaigher (2002) believe that African cultures often embrace supernatural rather than scientific or medical explanations for the onset of disease and are more concerned with cures than preventative measures.

4.3.3 Sunburns

Luthando said she walks almost ten kilometres to and from school every weekday. She said that in summer she endures the sting of the sun's rays on her vulnerable skin. She tries to wear protective clothes but because of the ignorance about other options of protecting herself, protective clothing seems not enough to stop the stinging sensation of the burning sun in summer.

> *Luthando: I don't know sunscreen, I have never heard of it, I just get burnt. I lost a hat that Ma'am Shabalala bought for me, I only have a cap but it is not allowed here*

> *at school. After three days my skin gets back to normal. In summer it is worse since my school is quite far from home and I walk to and fro.*

Lack of melanin pigment in people with albinism causes these people to be sensitive to sunlight. If they spend a lot of time under direct sunshine their melanin deficient skins develop wrinkles, lentigines, actinic keratoses, and epithelomata which may result in early death (Schultz, 1998). Luthando is perceived to be unaware of the long term dangers of the sun in her life; she is only taking pleasure in knowing that her skin gets back to normal after three days. Hong, Zeeb and Repacoli (2006), and Pooe-Monyemore (2007), further stated that the ultraviolet exposure is highly detrimental to people with albinism as the most exposed body parts such as the face, neck, and shoulders suffer from lesions. These skin lesions include sunburns, blisters, and superficial ulcers.

Medical care is seen to be incomprehensive due to the lack of awareness of the implications of sunburns and the lack of sunscreen lotion provisions. This is highly necessary to most of the participants considering the lack of finance from their families and the high cost of protective products.

Mthandeni shared with the researcher similar experiences and even blamed his sensitive skin for not having friends at school.

> *Mthandeni: I have seen that other learners make friends as they play along, like in a soccer game – which is the only sport that is played here at school. I can’t play soccer, not that I can’t, I can kick the ball just like they do, but since it is played outside in the sun, I can’t join them because my skin easily gets burnt. I know they look at me and think I am snobbish, they just don’t know.*

The sunthreatening the health of people with albinism was seen to be robbing participants of the opportunity of social interactions with peers in play and other extra-mural activities in schools. The holistic development of a child is enhanced through play (Morrisson, 2001; Bridges & Woodson, 2002). Henninger (1995) further states that play is an extremely significant way for children to learn about language, intellectual concepts development, social relationship building and understanding, strengthening physical skills and stress management. A child can escape negative emotions and stress challenges through play. The inability for Mthandeni and other participants to take part in outdoor activities could be the cause for them finding subjects difficult, especially mathematics which requires basics skills that are mastered through play. Gaigher, Lund and Makuya (2002) believe that isolation of LWA from outdoor sports and extra-mural activities because of their poor eye sight and skin sensitivity, robs them of cognitive and perceptual motor development stimulation.

Apart from walks to and from school, Zithande mentioned that it is in sports where she endures the sunburns.

> *Zithande: I play cricket and another sport which is more like karate. Netball is my favourite. At Adrin High I was playing netball and hockey, the sun was affecting me, it was painful but I did not care. My skin is strong, I don't apply sunscreen onto my body I just don't like it, I only used it once this year when I was at the beach. I do not play goal ball. Goal ball is for people who have eye problems.*

Participants in this study evidently were aware of their skins' vulnerability to sunburns. They said they wore protective clothes to avoid sunburn and none of them revealed the knowledge of skin cancer as the result of sunburn. Zithande was perceived to be risking this disease to prove that "*her skin is strong*" and mostly to see herself as "*normal*" (Goffman, 1963, p. 24).

4.4. Teaching and learning

All the participants utterly confirmed that they were not performing very well in their classes. They complained about their difficulty with subjects especially mathematics. Four of the participants reported that they had repeated some of the grades once or twice. Mthandeni said that he had never repeated a grade, and perhaps this was because he started schooling very late.

According to the experiences they shared with the researcher contributing factors like the attitude of community members, inadequate teacher support, and lack of teacher understanding of albinism were evident.

4.4.1 Attitude of community members

Community, teacher and peer attitudes consciously or unconsciously are perceived to be devaluating in nature. Baron and Bryne (1997) maintain that attitudes function as schemas cognitive frameworks that hold and organise information about particular concepts, people and events. They involve what people think about, feel about things and how they would like to behave, therefore they are learned.

Participants shared their stories of how their neighbours and community members negatively impacted their education.

> *Luthando: One day I was doing my homework at night and everything was quiet. I suddenly heard noises of drunken people shouting passing on our road. Maybe one of them saw the light still on in my home, because he started shouting… "Nawulomuzi onesishawa" meaning here is the house with a cursed gal. I could not finish my homework, I left everything right there and went straight to bed crying. I did not tell my teacher why I did not finish my homework. A few days after that incident, that man was hit by a car and died just by our gate. That is when my grandfather told us that he always shouted those words when he was drunk and passing by our house, his death was God's punishment. Fortunately I only heard him that once.*

The whole family here is viewed to feel stigmatised also by this encounter. Luthando's grandparents heard this drunken person a number of times but they never stood up to him to stop harassing them. This concurs with what Mak and Kwok (2010) found, that stigma by association is related to low self-esteem.

One of the participants shared her story of how she came to realise that she was different from other children and the trauma of being told she looked like someone she was so scared of.

> *Zithande: I remember I was in grade 2. It was a weekend I was at home and an albino woman came to my house, I looked at her and I got scared, I cried and ran away to the bedroom. At that time I did not understand I looked like her even if I looked in the mirror I did not realise because I was a child. So I told my mom there was a white woman in the house. This woman did not understand, I was a child, because I met her again one day on my way to school and she said I was her daughter - "here is*

> *isishawa looking exactly like me." I cried a lot and ran back home and refused to go to school because I thought I would see her again.*
>
> *One day as well I was waiting for my mom by the gate to take me to school and a man went past and said "ja sishawa" meaning hallow cursed girl. I didn't understand what that meant but I was hurt because I somehow knew he was teasing me and I cried the whole day at school. I told my mom but she didn't take me seriously. I then told my brother and he accompanied me, and we went to look for him but unfortunately he was nowhere to be found.*

Both these encounters impacted on Zithande's schooling as it caused her to be afraid to go to school and also the strange man caused her not to concentrate at school as she was so emotional about his labelling.

> *Mthandeni: I started school at the age of 11 because my parents were scared that I may be abducted or be hit by cars since my eyesight is so poor.*

Myths around albinism reveal that people with albinism are viewed as objects that can bring them either luck or bad luck. Attitudes of community members are associated with stigma and cultural beliefs. It is due to such myths that parents become sceptical about letting their children with albinism attend school due to the fear of abduction and labelling from their immediate communities. These children end up enrolling late in their lives.

4.4.2 Learning achievement

All the participants mentioned one or two subjects that they battled with in their classrooms. Noticeably, mathematics was a common subject that was more difficult.

> *Athandiwe: The problem that I have is with the maths subject, it is very hard.*
>
> *Mthandeni: I encounter difficulties especially when I have to read maps in geography and cartoons in English. I fail to see words in small fonts and faint lines in a map and I end up getting poor marks. This worries me because very soon I will be writing my matric exams.*

> *Nontando: I was doing some mathematics practice for the test we will be writing tomorrow. I'm very scared of maths, I usually don't get good marks in that subject; I try and try but…*
>
> *Siyamthanda: I used to pass maths and accounting but now my marks are dropping.*
>
> *Zithande: I don't have a problem with my eyesight; my difficulties are just the hard subjects…*

Most of the participants have in their school lives repeated a grade or two.

> *Nontando: She used to call me a white/red blind thing and always shout at me when I went closer to the board, as a result I repeated grade 3…*
>
> *Zithande: The year 2011 I repeated grade 9.*
>
> *Luthando: I repeated grade 1 because I seldom went to school*
>
> *Siyamthanda: When I was in grade 6 I could not even write my examinations and the headaches caused me to repeat that grade. I also repeated grade 1, the teachers said I had to repeat because I was too young but now that I think about it, it was not true because the very same teacher passed my twin sister who is dark skinned. My sister is now in grade 11 and I am still doing grade 9.*

These findings concur with the findings of the double case study by Dart *et al.* (2010) conducted in Botswana which found that learners with albinism in secondary school were underperforming and that has been the case since primary school.

4.4.3 Inadequate teacher understanding and support

Five of the participants could not remember having one-on-one personal contact with their teachers. They all utterly confirmed that the only communication the teachers had with their parents was through a report card at the end of each term. Zithande mentioned that her results for the second term were absolutely bad especially because her marks had dropped in English which was the subject she always did well in. She said she believes this was caused by her carelessness. When the researcher asked her if the subject teacher had talked to her about her poor performance she said ‘no’, and that none of the teachers mentioned it. The only person who scolded her was her grandmother at home.

Simple interventions like sitting the child with albinism in the front were initiated by participants themselves at secondary school level. Nontando mentioned that at lower primary school she was given a seat by the window at the far right of the classroom and the light coming in from the window made it impossible to see the board.

> *Nontando: Heeee! You know Ma’am, at primary school my teacher seated me near the window, on sunny days when the light came in through the window, it became totally impossible for me to see the board and when I could feel that my skin was beginning to burn from the sun, I would put my bag on the window to create a shield.*

Mthandeni had similar concerns and suggestions about the colour of the chalk teachers needed to use to help them see better what was written on the chalk board.

> *Mthandeni: It would be better if they [teachers] could change using the white chalk to yellow chalk to write on our green board or change the board from green to black so that we [LWA] can see as well.*

Participants seemed to have a lot to say about the chalk boards in their class rooms.

> *Luthando: I sit in the front, Ma’am said so, so I can see the board but I always rotate depending which side of the board the teacher is writing, no one complains because as soon as I finish writing I go back to my seat.*
>
> *One day I was sitting at the back writing something I cannot remember what it was, my teacher asked the class to read, but I did not because I was busy, he then asked me to read alone. I stood up and walked towards the front, the whole class made noise saying where are you going? Sit down; you just want to show off. Sir said I must read, when I tried to, he said “Nxxx! You stupid thing go and sit down.”*

> *Zithande: Teachers write too many notes on the board and they erase the board to write more while I haven't finished writing. I will have to copy from others, sometimes my friends would write for me. Luckily I can read somebody else's handwriting.*
>
> *My class teacher whom I think had a problem with me, she just did not understand my situation yet I expected her as a teacher to understand more than the pupils, like the other day we were writing notes from the board, I went and sat in the front so that I could see but she shouted "what are you doing in the front, you are blocking pupils behind you go back to your seat'' [imitating a teacher's small voice] when I tried to explain she was just not interested. From that day I never concentrated in her class I was quiet all the time. I was still new at this school, I wanted to report her but I was scared, I just gave up that class and I did not care.*

All the participants agreed that typed and handed out notes were the best for teachers to use. Even though some of the teachers did use this method, they still did not understand that small print is like "spilled ink" on the paper, as Nontando puts it.

> *Siyamthanda: I would be happy if the teachers could increase the font size on the handouts they give us. We always ask them to do so but I don't know, they just don't understand. What they do is they enlarge the paper to A3, but that is not what we want, we want only the font enlarged. I am glad because they do this here in this school where everybody has his/her problems, if it was in a mainstream school I would not take the A3 paper because it would have made me really feel different. You can imagine Ma'am the noise of the A3 paper as you page and turn it. Now I no longer care about anything because I have been treated badly ever since even by my own siblings.*

Lund and Gaigher (2002) stated that self-image and self-worth in LWA who are enrolled in a special school is enhanced by support and teachers' positive attitudes. Findings in this study revealed that self-worth, self-image, and self-esteem are basically determined by the normals around the learner with albinism. Siyamthanda was in the class of learners with other disabilities, this boosted his self-esteem to the extent that when he was given a different sized paper he did not feel different from other learners with other disabilities.

Zithande agreed that it was much better to read notes from a typed handout because if she could hardly see she was able to bring the paper close to her eyes, but the problem began when they had to share a book in class.

> *Zithande: My other problem is when we have to share reading a book. I cannot do that because when I am reading I have to bring the book closer to my eyes therefore the other learner won't be able to see, I would end up not reading and just write whatever summary is written on the board which is not enough when preparing for the examinations.*

In a focus group discussion, Siyamthanda suggested that teacher intervention could eliminate the ill-treatment of LWA in schools.

> *Siyamthanda: Teachers could protect us against bullies by talking to all the children at school even in the classroom explaining to them that the other child with albinism is exactly like them, and teaching them about albinism and the problems that people with albinism face instead of mocking them in the presence of other learners.*
>
> *…we were in the class reading a novel which was in small print, I couldn't see a thing. The teacher told us this will form part of our marks so when my turn to read came, I couldn't read properly. I tried my best but [raising his shoulders]. The teacher said I was "dom" meaning stupid, in front of the class and continued to say she wonders how did I make it to this grade since I cannot read, I am counting words.*

In the focus group discussion some participants mentioned that not all the teachers are inconsiderate. They tabulated few incidents that evidently displayed concern and a will to assist and Zithande even went to the extent of advising other participants to ask for those interventions from their teachers.

> *Zithande: Whenever Ma'am Ngcobo gave us a project or class work to do, she always postponed my due date.*

> *Athandiwe: My grade 1 teacher Ma'am Mthembu knew I could not see well, she met my mom and asked her to take me to the doctor, and they organised glasses for me. She always took good care of me and did things for me. She advised me to use a hat and brought me nice things. She is the only teacher I miss a lot, she is late, and she passed away when I was in grade 3.*
>
> *Siyamthanda: Miss Gutshwa really cared about me e.g. she asked what she could do for us if we could not see the board, when we were writing the exam she came to check if our paper had been enlarged, I am impressed she really treats us very well.*

Some participants in the study are enrolled in a special school and some in mainstream schools. Teachers are expected to know about medical challenges, in theme one, that the LWA faced were to better accommodate them in their classrooms. In this study, irrespective of the school the participants were enrolled in, teachers were not able to holistically include and support the participants. Failure in so doing was detrimental in the development of their self-images and self-esteem. The embarrassing moments that participants endure in their classrooms by their peers and their teachers showed little to absolutely no understanding of albinism and inclusion. Some teachers even refused to share their spaces close to the board with the participants.

4.5 Discrimination and prejudice

Participants reported many discriminatory and prejudicial accounts in their lives that brought about different emotions and therefore different reactions and behaviours evolved in response to those accounts.

4.5.1 Segregation

Zithande shared an experience he had at one of the boarding schools he once was enrolled in. This experience, as he puts it, was exactly the same thing that he read about in South African history books. He talked about acts of segregation that the "Darkies" learners without albinism created against "Whites" LWA in the hostels.

> *Siyamthanda: …we were always separated from the dark skinned children, told not to share with them things like soap. When playing soccer, albinos would be*

> *together and the other kids would be on the other side, we were not mixed, other learners were scared albinism is contagious.*
>
> *You know when I hear people talk about days of apartheid in South Africa I think it is exactly like it happened at that school. There were showers only for dark skinned and showers for albinos, sleeping rooms also were separated.*
>
> *This caused many fights about "Blacks" against "Whites". We as albinos developed a strong bond to fend for each other. An injury to one of us was an injury to all of us.*
>
> *…we would fight also about the myths around albinism that they usually teased us about. One that mostly gets to me, even now, is the one that people believe that having sex with an albino cures AIDS.*
>
> *Athandiwe: Some children were playing with a ball, I asked to play with them and they refused saying they don't play with "abelungu" white people, I was disappointed and I silently went back to class.*

Labels used to describe a person's skin colour points to discrimination and stereotyping even between people of the same race (Gabriel, 2000). Learners without albinism showed cruelty and prejudice towards LWA only because they were different from them. This appeared to be painful to the LWA because like all other children they wanted to feel loved and accepted by their peers. These findings align with what was found by Gaigher *et al.* (2002) in the study of LWA in a special school in Limpopo, that most of the challenges LWA experience at school do not result from physical differences but from the manner in which others respond to those differences.

4.5.2 Self-concept

All the participants in this study endured being called deforming and derogative names by not only their teasing peers but also adults and disappointingly even by their teachers.

> *Nontando: I repeated grade 3 also but the reason for repeating grade 3 was because my teacher did not help me, she was irritated every time she looked at me, she called*

> *me ‘little pig’ ‘red thing’. Learners also gave me a hard time calling me “umlungu” meaning white lady.*
>
> *Luthando: Other children call me white gal and “isishawa”. ..Sometimes they call me Helen Zille and deny it if I report them.*
>
> *Athandiwe: There are learners who call me ‘umlungu”, I reported them and the teacher hit them. They have stopped teasing me.*
>
> *Zithande: On our way back home from school I had a conflict with Sbo. The next day Sbo lied about me to Dolo and all the other girls, they came to me with a lot of questions and insulted me but I kept quiet because there was a lot of them obviously they were going to win the battle if I could have tried to fight. Dolo said “you’re forgetting that you’re the only one who is white here do you know we can beat you and you will bleed at the same time.”*
>
> *The next day in the class I was sitting in front, I heard Sbo starting a conversation behind me saying here in this class we have a white person, a monkey, and many other names they call me. I was so embarrassed, hurt and disappointed in a way that I couldn’t even look back or cough or do anything I remained in the class the whole day until home time, I did not take my break and lunch.*
>
> *Mthandeni: They call me “gqonqi” meaning a white man and some call me a doll. They say so many things and comment when I am around obviously they want me to hear. That hurts a lot but I do not confront them I just keep quiet.*
>
> *I have no problem with skin colour, what hurts the most is the names they call me. It hurts and irritates so much so that sometimes I just sit by myself in the class and say nothing to anyone.*

All of the participants in this study experienced name-calling by their peers. The name of “umlungu,” meaning the white person, supersedes them all. NOAH (2005) argues that name calling, teasing and insensitivity results from the lack of knowledge, curiosity, a genuine desire to learn and an inability to pose questions constructively. Humiliation and other discriminatory acts resulted in anger and loneliness.

> *Siyamthanda: Lots of people here at school and at home say things that I really don't understand, they call me by different names, and they say I am different from others. At home as well my siblings call me names and say I don't belong to this family but I'm not the only albino in the family our old brother the first born about 32 years old is also an albino but he didn't stay at home because of work. I have a twin sister, she is not an albino our relationship is good but I don't discuss my problems with her. My other siblings used to say I am an outsider, treat me differently telling me that I do not belong to the Cele family, this is not my home, Mr Cele is not my dad he adopted me.*
>
> *They talk in such a way that sometimes I think my parents are hiding something. My big brother who is also an albino is probably my dad and we're both not members of this family.*

The overprotection of parents causes a great deal of animosity between siblings (Blankenberg, 1997). Siyamthanda mentioned that when he is back at home during holidays, his parents spend most of their time with him.

> *…the things people said to me, calling me "umlungu" – white man, made me wonder what kind of a person I was. I was not sure whether I was Black or White…….but I thought….. I am not White……..I don't speak English. Who am I really?*

As Siyamthanda grew older and went to a secondary school he was determined to prove that he was somebody and that "different White" somebody as they called him, was so perfect that he did not expect to be pitied but could make donations to the ones in need.

> *Siyamthanda: People know us as disabled people so we only accept stuff given by normal people in the form of gifts, donations etc. So what I did, I mobilized some of my friends and we fund raised, collected money and we gave it to one of the crèches just to support them. This and many other things I do here at school make my parents proud of me and they keep telling me that I will be a leader one day. They say since I have this white skin I should always do well because my skin makes me stand out from the crowd, every little thing I do people will notice me. I spend a lot of time with my parents during holidays when I am back home because I do not have friends in our neighbourhood.*

Siyamthanda's self-esteem is perceived to be enhanced by his father's words of encouragement. Our sense of who we are and our social relations are connected to our bodies

(Jordaan & Jordaan, 1998). For Siyamthanda, his stark white skin influenced his actions to do well. Dell-Orto and Marinelli (1995) point out that body image and self-concept play an important part in an individual’s ability to come to terms with disability.

4.5.3 Low self-esteem

The abovementioned acts of prejudice and discrimination qualified to cause some of the participants to have a low self-esteem. When the researcher asked Luthando if she had school friends, this was how she responded:

> *Luthando: I do, well I don’t know if I could call them my friends because I don’t know if they love to be my friends.*
>
> *Mthandeni: Sometimes when we are put together, I mean learners from different classes are placed in one big class, some students say bad things and they act like they are speaking to themselves but when I listen closely I pick up that they are talking about me, like one day they said someone here doesn’t belong, he is not South African, they can tell by just looking at him, he crossed the border and came here. I quickly picked up that they were talking about me because I’m the only one different from them.*

The researcher tried to highlight some of the things the other learners said that could make Mthandeni see that they may have been talking about somebody else, like *“…he is not South African…he crossed a boarder and came here…”*. He insisted that he was the only one in his class who was different.

> *…they ask me why my eyes move so fast, I don’t like these questions especially if I am in a crowd. They make me feel small because I can’t tell if they want to know or they just want to make fun of me.*
>
> *Nontando: I do have friends, I actually am friendly to everyone but my so-called friends sometimes hurt me and I have become sceptical about our friendship and I hardly play with them. One day we were playing “ushumpu” meaning the game that is played almost like cricket only the ball (usually a self-made plastic ball) here is hit*

> *by hand, I could not catch the ball. I went looking for it but I couldn't find the ball. Sthe came and picked it up in front of me and she screamed asking if I am blind, how come I couldn't see the ball in front of me. She continued screaming saying these white people who speak isiZulu are blind. I cried a lot and I never played with them again, I was afraid I won't catch and lose the ball again.*

Maslow (1970) is of the idea that self-esteem and acceptance contribute remarkably to people's experiences of dignity. Section 10 of the South African Constitution stipulates that "Everyone has inherent dignity and the right to have their dignity respected and protected" (South Africa, 1996). The participants' rights and dignity were evidently infringed upon and this contributed to their low self-esteem. The low self-esteem from participants was also due to the differentness of their skin colour which is highly visible and prone to stereotypical evaluations. Their social relations are poor because they feared rejection from other "normal" learners during sports and extra-mural activities (Goffman, 1963, p. 4).

This made the participants feel stigmatised on the basis of their skins. Their low self-esteem is perceived to be associated with the high visibility of their skins which is a deviating characteristic from "the normal characteristics in the category" of Black learners (Goffman, 1963, p. 4). For such reasons Gaigher *et al*. (2002) view stigma as a barrier to social integration. The perceived internalised stigma seems to be causal to the reduction of self-worth and psychological distress experienced (Herek, 2009) by the participants in this study.

4.5.4 Search for a sense of belonging

Generally learners change schools when they change phases, such as from a primary school to a secondary school, and they get mixed emotions of excitement and anxiety about the forthcoming change. Participants shared that ill-treatment and stigmatisation caused them to frequently change schools in search of a school that would be more comfortable and a school that would not make them feel they were different from other learners. Excitement to them was never part of the equation. Changing schools to them came with a lot of stress and anxiety.

> *Zithande: Changing schools was not easy for me but it was necessary. I could not stay in a school that belittled me but as it kept happening in all the schools I went to I started to get stressed and worried every time I had to move. I wish somebody had prepared me by telling me that I would come across repeaters who would bully me, that I should be kind but not too kind because they would take advantage of me. I wish somebody had told me that other children would stare at me in my class and wait to see how I react, look at how I write, ask silly questions just to come close to me, and some will ask me questions about all the rumours they once heard about albinos.*
>
> *The first school I went to was at a place called Emalahleni, unfortunately teachers failed to accommodate my situation. I then moved to Ntshiso Primary and then Adrin High where I experienced the same problem. …the second year they changed my class teacher then everything changed but I was no longer comfortable. I then moved from Adrin High to this school. I would have still been in my previous school if I was not abused by my teachers.*

Childrenhave a right and generally expect to be loved and accepted by the adults and peers in their lives. Due to the stigma around albinism that the participants found themselves carrying on their shoulders, they were always anxious and stressed when they had to meet new people. They were aware that their “undesired differentness” was readily apparent to those people and anticipated immediate negative evaluations (Goffman, 1963, p. 3). Despite the discrimination and labelling Zithande endured in Adrin School she never gave up on her education, she continued to search for the school she would feel comfortable in. This contradicted with both studies of Braathen and Ingstad (2006) and Pooe-Monyemore (2007) who that found that ill-treatment and labelling by teachers and learners resulted in learners staying away from school.

> *Athandiwe: I was very scared when the time to change schools came, I did not know anybody in this school and I was scared that the children would tease me. I would have loved it if there was another child with albinism in this school. On my first day in this school I very quickly made friends because at home time on the same day I saw a girl who was my home girl. She became my friend and introduced me to her other friends. Other students were staring at me, some making fun of me and calling me “umlungu” and some asking me lot of questions.*

> *Nontando: I was very anxious about coming to this school I was not sure how they would treat me because the school was new to me, what kind of life I would live, maybe children would stare at me, laugh at me etc.*

Dart, Nkanotsang, Chizwe and Kowa (2010) maintain that primary schools should ensure that the transfer to secondary school is made as smooth as possible by communicating any necessary information to the new school. An arrangement of giving LWA a chance to visit the new school in advance to their move to familiarise themselves with the surroundings would also be of great assistance in the attempt to alleviate stress and anxiety.

> *…otherwise I was happy that I will be protected, I will not have to worry about strangers who would come by our house or try to talk to me on my way to school. Ma'am I'm sure you know about the myths around albinism….people think killing and selling body parts of an albino will make them rich, and that sleeping with an albino will cure them of AIDS.*
>
> *One day when I was at home with my younger siblings, a car with dim windows came by and parked at our gate. They called us, I thought it was our uncle; I went closer because I could not see from a distance, and they were total strangers. I ran back to the house and locked myself and my younger siblings inside just like our parents always told us to do.*

Fear due to myths around albinism is viewed to be one of the reasons parents decided to enrol their children in special schools that are also boarding schools. Knowing that their children are receiving education in a protected environment gives them a sense of relaxation. The special schools that some of the participants in this study went to, had covered walkways providing shade from the harsh tropical sun. Not much educational support from the teachers was mentioned though, except for font enlargement of handed out notes.

> *…when I came to this school this year January, a boy told me he loved me. I was so happy to know that a dark skinned guy knows that I am human and thinks that I am beautiful just like other dark skinned girls but I didn't fall in love with him [smiling].*

The researcher realised there was a risk of the participants being easily charmed into sexual activities by dark skinned people because of their eagerness to prove that they were as attractive as other dark skinned girls. According to Stuenkel and Wong (2012), there is a high possibility for people with disabilities to engage in sexual practices and get infected with HIV because their determination for attachment with other human beings becomes more significant than the need to protect themselves.

4.5.5 Physical harm

Corporal punishment has been abolished for more than eighteen years yet teachers evidently still apply it in schools. This is confirmed by participants as they shared with the researcher their experiences of physical harm by teachers at school.

> *Mthandeni: We were doing a new section in class; each of us had to read what was in the handout and present it on the board. I told my teacher I could not see, as the writing was too small. He said I was lying and I was making a fool out of him, how come I am the only one who could not see, he went to get a stick and he hit me. I went out of the class; he followed me calling me names like "red winter pumpkin". I was then called to the office and as I explained what happened, he kept saying I am lying, I am just rude.*

> *Nontando: When I was still in the mainstream school my teacher slapped me in the face, she said you white blind thing, get out of my class, I went out and stayed there until break time.*

Participants in schools were perceived to be seeking approval from others and were stressed by their disapproval. Discrimination and prejudice they experienced was seen to be decreasing their self-worth which was necessary to enhance self-esteem in order to favourably evaluate the self (Mabore, 2007). One participant reported confusion with self-identity because of forever being labeled "umlungu," the White man. Like most other participants he found himself socially disadvantaged because he was neither Black nor White. The community, including teachers and peers at their disposal, shaped this identity confusion. Goffman (1963) explains that the problem is not with the identity of the person rather it is the society that constructs that identity as stigmatised.

4.6 Navigation strategies

Through experiences participants shared with the researcher and together in a group discussion, it was evident that the adversity of having albinism has brought remarkable stress in their lives. Unconsciously or consciously participants developed the emotional, physiological, behavioural and psychological responses to help them cope with the stigma-related events.

Participants in this study have all reached the adolescence stage. It is at this stage that Erikson (1968) argues that the task of developing a stable, coherent identity is vital. He further states that the adolescent must be able to use formal operational reasoning within a context of expanded social experiences to develop the sense of self that not only includes the similarities but also the differences between the self and others. Participants to some degree have reached this stage of cognitive development as they are perceived to be gradually developing their coping mechanism with stigma through their navigation strategies.

In this study six strategies of reaction LWA used to respond to stigmatisation have been identified. These strategic methods were drawn only from this study with associated labels based on the participants' quotes. One response may alter the next or it may complement it and they may be used simultaneously. The overlap of these responses may consequently play different significant roles in the person's response to a stressful encounter. The navigation strategies found were:

- *The avoiders* ~ those who withdraw or disengage from stigma-related stressors.
- *The deniers* ~ those that deny the existence of the problem.
- *The dis-identifiers* ~ those who choose not to identify themselves with the stigmatised group.
- *The accepters* ~ those that accept themselves and all that come with who they are.
- *The emotion regulators* ~ those who regulate their emotions to avoid anger and anxiety.
- *The emotion expressers* ~ those who express their feelings about a particular situation.

4.6.1 The avoiders

Participants navigated their experiences by not engaging themselves with other learners who stigmatised them at school.

> *…they call me "gqonqi" meaning a White man. They say so many things and comment when I am around; obviously they want me to hear. That hurts a lot but I do not confront them I just keep quiet.*
>
> *I have no problem with skin colour, what hurts is the names they call me. It hurts and irritates so much so that sometimes I just sit by myself in the class and say nothing to anyone.*

Seemingly Mthandeni adopted this strategy from his parents as we have learned that he started schooling at the age of eleven.

> *I started school at the age of 11 because my parents were scared that I may be abducted or be hit by cars since my eyesight is so poor.*

Mthandeni's parents' anxiety and worry about his well-being made them decide to keep him at home to avoid any form of harm that the outside world could bring to him. Crocker and Major (1989) maintain that if a stigmatised person fails to avoid stressful situations, they end up withdrawing socially. By withdrawing socially they avoid social comparisons with stigmatising group members. This navigation strategy may result from a stigmatised person's acknowledgement that others are doing better than him (Crocker & Major, 1989).

4.6.2 The deniers

For Luthando the teasing and name calling was hurtful but she chose to minimise the stress by denying the hurt and pretending like there was no discriminatory occurrence whereas there was objective evidence that a particular occurrence was due to prejudice. Goffman (1963) calls this response covering because the stigmatised person acknowledges the condition but minimises the consequences of felt stigmatisation. Stuenkel and Wong (2012, p. 57) maintained that people who are deniers are found to use humour to cover their anxiety and "avoid awkward encounters."

> *Luthando: One day on our way from school, one of my friends Sindi was wearing a white T-shirt written in red on the front. She was with her sister Zodwa. She pointed at me and said "Hey check this girl she is as White as my T- shirt!!" All the kids on the road laughed, I laughed as well, but when I got home I cried.*

Major, Richards, Cooper, Cozzarelli and Zubek (1998) caution that the denial behavioural response that Luthando adopted is largely related to an increased psychological distress that may include maladjustment and physical symptoms. On the other hand Crocker, Major, and Steele (1998) promote and define dis-identification as the process of ceasing to base one's personal identity on a stereotyped domain.

4.6.3 The dis-identifiers

One participant that was seen dis-identifying herself with her stigmatised group of LWA is Zithande. In trying to exclude herself from the stigmatised group she ended up giving contradicting statements.

> *I don't have a problem with my eyesight; my difficulties are just the hard subjects…*
>
> *…I do not play goal ball. Goal ball is for people who have eye problems.*
>
> *…I cannot share a book because when I am reading I have to bring the book closer to my eyes therefore the other learner won't be able to see.*

Zithande's navigation strategy of dis-identification was a cognitive behavioural psychotherapy that redefined the meaning of a threatening and stressful event (Gottlieb, 1997).

> *…some people assume that I only speak English, anyway I was speaking only English and some thought I was coloured, I don't look like other albinos. My skin is a little dark compared to other albinos and smooth…*

4.6.4 The accepters

Most participants related to this navigation strategy of accepting who they were.

> *…I really don't care. I have accepted myself; it does not hurt anymore what people say. I left the past in the past. I know I am an albino and I won't change.*

> *…well previously I was a child and did not understand but now I'm used to it. I have accepted myself and my family told me to ignore what people say to me and tell those people I'm more beautiful than them.*

In this theme most participants were viewed to have accepted themselves as LWA. Caver, Pozo, Harris and Noriega (1993) in their study of cancer patients concluded that acceptance is related to a positive psychological adjustment. Acceptance is a less adaptive strategy for dealing with stigma stressors simply because these stressors are more constant and pervasive than other types of stressors (Miller & Kaiser, 2001).

4.6.5 Emotion regulators

Participants revealed that a feeling of being stigmatised evoked certain emotions like anger and hatred. Failure to regulate these emotions could be detrimental to successfully overcoming prejudice (Steele & Aronson, 1995).

> *… I would advise any other LWA to always calm himself down and tell himself that he is exactly like others; the only difference is his skin colour. I would let him know that there are words that they will call him but he must try not to be hurt by those names because he can end up hating himself. I would tell him to ignore everything they say to him, they will be confused and ask themselves why are you not crying or fighting because they worry and abuse you so much.*

Miller and Kaiser (2001) argue that by not allowing emotions to reign, a stigmatised person is better able to concentrate on behaviours that that will reduce the impact of prejudice on the particular situation.

4.6.6 Emotion expressers

Unlike an emotional regulator, an emotional expresser openly displays the emotions about the particular situation at hand. Collective action is largely associated with emotional expression. Those who organise collective action typically share a hostile and dissatisfied feeling about the particular situation (Brewer & Brown, 1998).

In one of the experiences Siyamthanda shared with the researcher he mentioned how they teamed up as LWA against the “normals” in his school (Goffman, 1963, p. 74).

> *You know when I hear people talk about days of apartheid in South Africa, I think it is exactly like it happened at that school. There were showers only for dark skinned and showers for albinos, dormitories were also separated.*
>
> *This caused many fights about Blacks against Whites. We as albinos developed a strong bond to fend for each other. An injury to one of us was an injury to all of us.*

Siyamthanda and his group of other LWA had a positive expectation that their collective action would change the way other learners viewed them. If they fight they would know that they are also people like them, if they think they are the only ones who can be rude or fight they must think again.

In the attempt to control anger and other emotions some participants adopted the strategy of emotion regulation and emotion expression. Emotion regulation and emotion expression are responses that Miller and Kaiser (2001) find to be critical in gaining primary control through compensation. Compensation involves adapting one’s social interaction strategies in an attempt to achieve goals despite the existence of prejudice (Miller & Myers, 1998).

4.7 Conclusion

This chapter looked at the four themes that emerged during data analysis. Data gathered revealed that in spite of other teachers' attempts to include LWA in their classrooms, these learners still feel stigmatised and discriminated against. Participants in their different ways found within themselves navigation strategies that helped them through those prejudicial stigma-related experiences. Stuenkel and Wong (2012) argued that stigma does not attach universally to individuals with marked conditions as some individuals appear resistant to stigma, identifying flaws in the society conveying negative beliefs.

The next chapter presents conclusions of the study, briefly comments on the limitations of the study and offers recommendations.

CHAPTER FIVE

CONCLUSIONS, LIMITATIONS AND RECOMMENDATIONS

5.1 Introduction

In the qualitative search for data to answer this study's questions regarding the experiences of LWA and how they navigate those experiences, data received was analysed and a qualitative design was attempted. After the analysis of the data elicited from the participants, certain conclusions were drawn in relation to the literature review and stigma theory. It was as a result of these conclusions that the recommendations have been made. This chapter will present these and also note the limitations of this study.

5.2 Conclusions

The conclusions regarding findings are discussed according to the main themes:

5.2.1 Medical concerns

All the participants in this study have visual difficulties. Very few of these problems were correctable by the use of glasses. Most participants reported that the glasses they once used were not helping their visual acuity and they stopped using them. It was also noted that out of concern one teacher presented glasses to the participant without proper testing by the eye care specialist. One participant who narrated that her teacher met with her mother and advised her parent to take the participant to the specialist doctor for eye treatment, is the only one who said the glasses the doctor prescribed helped her eyesight. The researcher also noted the possibility that the participants could be lying about the glasses not helping them. NOAH (2010) stated that LWA and other learners with low vision tend to break, hide and lose their glasses to avoid using them.

Except one, all the participants reported to suffer from frequent headaches, these headaches are viewed to be related to their eyesight difficulties. Participants who are boarders at a special school are viewed to be spared the torture of the stinging sun rays that the participants attending mainstream schools endure every summer weekday going to school. Sadly the latter participants come from families with financial constraints and could not afford sunscreen creams and other protective clothing.

The threatening sun prohibited the participants to engage with other learners without albinism in outdoor extra-mural activities and sports. Again here participants in a special school are viewed to be more privileged since their school has teachers who are able to introduce them to other supplementary indoor games and games designed for people with eyesight problems.

5.2.2 Teaching and learning

Stigma borne by the participants not only affected them but also their families. This gave the researcher the probability that the parents who did not enrol their child (this study participant) at the nearby school until he was eleven years old, were trying to conceal having a child with albinism and therefore avoiding community labelling and ignorant judgments towards their family. Some family members are seen to be angered by such judgmental labelling directed to the participants and strive to physically avenge them. These inconsiderate remarks whether uttered consciously or unconsciously, impacted negatively on the education accessibility and attainment for the participants.

The participants’ ages compared to the grades they were doing showed that they were lagging behind by one to four years. Data collected revealed that most of the participants repeated grades. Some blamed their teachers’ ill attitudes and some blamed the prior discussed medical issues as the causes for their poor learning achievements. For all the teachers, the board seemed to be the main teaching instrument used in the classrooms; this posed a problem to the participants because the board in all classrooms was situated far from the learners’ desks and participants battled to see what was written on them.

5.2.3Discrimination and prejudice

Discrimination experienced by the participants in this study was viewed to be the source of their insecurities and lack of self-esteem. Moreover, it brought about confusion of who they were. Teachers, whom parents trusted to protect their children in their absence, were sadly viewed to be at the centre of the prejudicial acts against the participants.

Moving from school to school was seen to be caused by the feeling of differentness in that particular school participants left. Moving away, seeking the school that would make them feel they were one of the others, came with a lot of anxiety and stress but their will to continue with their education pushed them to keep going.

5.2.4 Navigation strategies

All the participants are viewed to have reached the transitional stage of physical and psychological development. They each adopted certain navigation strategies to help them cope with stigma that is associated with their condition. Mastering these strategies, which the researcher assumes will grow stronger as they grow older, will help them to not only cope at school but all through their lives.

However, the researcher is very uneasy about the reliability of the strategies that the participants who attend special school have adopted because they adopted them in a controlled environment of a special school where risks of discrimination and prejudice are minimal. According to Camp, Finlay and Lyons (2002), if one creates a strong bond with people who share similar conditions, one develops feelings of normality. When one is out of the closed interaction proximity with those people and is in contact with the outsiders, the isolation process surfaces again (Stuenkel & Wong, 2012).

5.3 Limitations of the study

Two methodological limitations in this study have been identified.

- The general population of learners with albinism is limited and this consequently limited this study’s sample size. Six learners with oculocutaneous albinism were purposively selected at Umlazi District. This sample size limited the generalisation of the study. However the researcher believed it was essential to conduct research on this topic to give voice to this small group of people with the aim of sensitising all structures concerned about the challenges and needs of LWA.

- Inadequacy of research studies on the same topic in South Africa, KwaZulu-Natal in particular, drove the researcher to citing studies done outside South Africa and overseas. Few of the studies the researcher found on people with albinism in South Africa were based on their experiences in their communities and there is a huge shortage of recent studies. More research studies need to be conducted to investigate the school lives of children with albinism to contribute to the better understanding of their joys and challenges.

5.4 Recommendations

Based on the findings of this study, these recommendations are made. They will be presented thematically. These recommendations require a collaboration of different governmental departments and other structures concerned but initiation by teachers will hopefully speed up the processes of implementation.

5.4.1 Medical concerns

Teachers should:

- Advise parents of LWA to take their children to eye care specialists for proper eye testing.
- Make a follow up to ensure that the LWA are referred to eye care specialists in nearby hospitals and are treated free of charge.
- Advise parents of LWA to visit the servicing social worker in their area to request monthly supplies of sunscreen lotions and long beamed hats to LWA.
- Encourage LWA to wear contact lenses, especially teenage students who have come to be conscious about their looks.
- Advise LWA to take constant breaks when studying to relieve strain on their eyes and therefore avoid the possibility of headache attacks.
- Advise LWA to wear protective clothing and play under the shades.

5.4.2 Teaching and learning

Teachers should:

- Enlarge font in all notes to be handed out to LWA.
- Maximise colour contrast between the object and its background. On black boards, white chalk should be used and on green boards, yellow coloured chalk should be used for more visibility.
- Allow LWA to choose sitting positions in class that they deem suitable for them and give them authority to move closer to the board to see better.
- Grant LWA extended time to finish their class activities and projects. It is also highly recommended that teachers explain to the class why that is done to avoid other learners thinking that LWA are receiving preferential treatment.
- Mind language they use especially if directed to LWA in class. Dart *et al.* (2003) advised that teachers should avoid asking questions like “Can you see this?” They should rather say “Tell me what you see here.”
- Never ask LWA to share text books because they need to bring books closer to their eyes for better view, if they are sharing with other learners there is a risk of them pretending they see just to accommodate other learners they are sharing the book with.
- Involve them in daily classroom chores and assign some leadership roles to them, in that way they will feel they are part of the group. Vaughn *et al.* (2000) maintain that it is important that learners with special needs get ample opportunities to display their strengths; in so doing they get a chance to be the helper instead of always being helped.
- Apply early in the year for time extension through the Department of Education for LWA who will be writing their national matric examinations that year.
- Allow LWA to wear their hats even indoors to protect their eyes.
- Organise activities in school to sensitise other learners about albinism. It is also recommended that LWA are invited to take part in those activities or share ideas, this will ensure that the LWA will not be offended by any of those activities.
- Form a learner support team that will ensure constant contact with the LWA and class teacher to check if they need any further interventions.

5.4.3 Discrimination and prejudice

Teachers can boost self-esteem in LWA and eliminate discrimination against them by:

- Giving them information about different support groups for people with albinism and organisations like Albinism Society of South Africa (ASSA).
- Arranging pre-visits by the LWA to the school they are to be enrolled in the following year for orientation to minimise anxiety. This will also prepare teachers in that school.
- Encouraging albinism activists to address communities about issues of labelling, discrimination and demystifying the myths.
- Encouraging family members to be supportive and build up a strong support structure for them.

Implementation of the above recommendations will exempt pressure in LWA to even exercise their navigation strategies.LWA can not only rely on what the teachers, parents and other stake holders can do for them, they also need to actively involve themselves and take action in the eradication of misconceptions about albinism.

5.4.4 Taking self-actualised action

LWA should:

- Start or take part in awareness campaigns that educate their communities about albinism. In a study by Pooe-Moyemore (2007) findings established that such campaigns have a huge positive impact on attitudes of the community to people with albinism.
- Enter competitions such as the one that was open to grade 11 and 12 learners which was in the Sowetan Newspaper (2007), sponsored by Developmental Bank of Southern Africa, Albinism Society of South Africa and the Department of Health where learners write essays that are aimed at raising awareness and crushing out myths and superstitions about albinism.

- Follow the lead of other activists with albinism using modern technology to form support groups. One LWA in a study by Wan (2003) created a website relating historical facts about people with albinism and answered questions from other children with albinism, many children benefit from this site.

5.5 Conclusion

In answering the research question, seemingly the participants in this study have encountered remarkable stigmatisation in their education journey. Despite their prejudicial experiences and low vision problems, they maintained their strong will to continue with their education. This study also deduced that coping with these experiences largely depended on their personally developed navigation strategies.

This study significantly displayed flaws in the interventions by teachers of LWA. The government clearly stated its commitment to Inclusive Education; teachers should take it upon themselves to bring this phenomenon to life.

This chapter concluded this study, identified limitations, and made recommendations that were particularly directed to teachers who have LWA in their schools.

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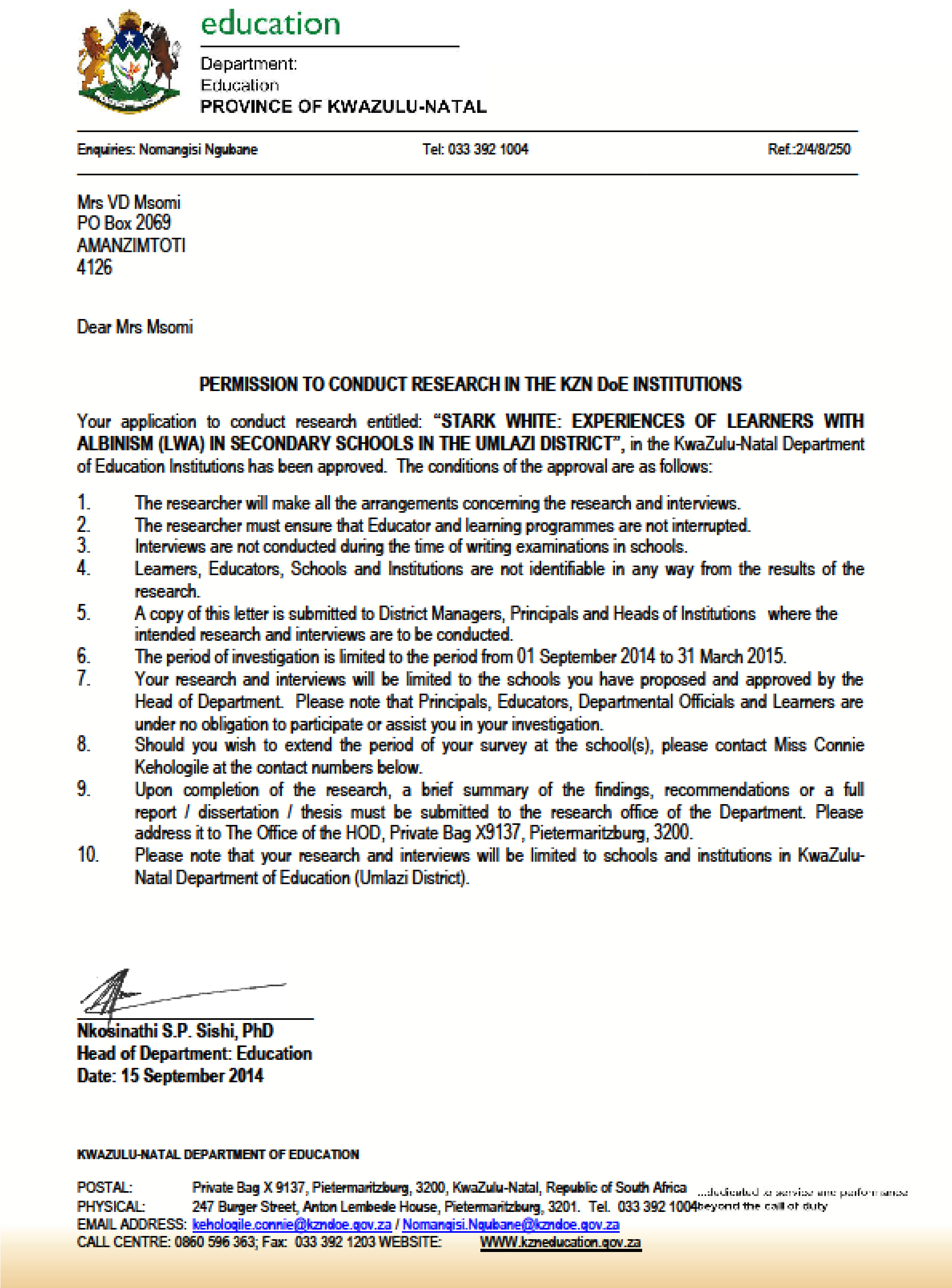
APPENDIX A



education
Department:
Education
PROVINCE OF KWAZULU-NATAL

Enquiries: Nomangisi Ngubane   Tel: 033 392 1004   Ref.:2/4/8/250

Mrs VD Msomi
PO Box 2069
AMANZIMTOTI
4126

Dear Mrs Msomi

PERMISSION TO CONDUCT RESEARCH IN THE KZN DoE INSTITUTIONS

Your application to conduct research entitled: **"STARK WHITE: EXPERIENCES OF LEARNERS WITH ALBINISM (LWA) IN SECONDARY SCHOOLS IN THE UMLAZI DISTRICT"**, in the KwaZulu-Natal Department of Education Institutions has been approved. The conditions of the approval are as follows:

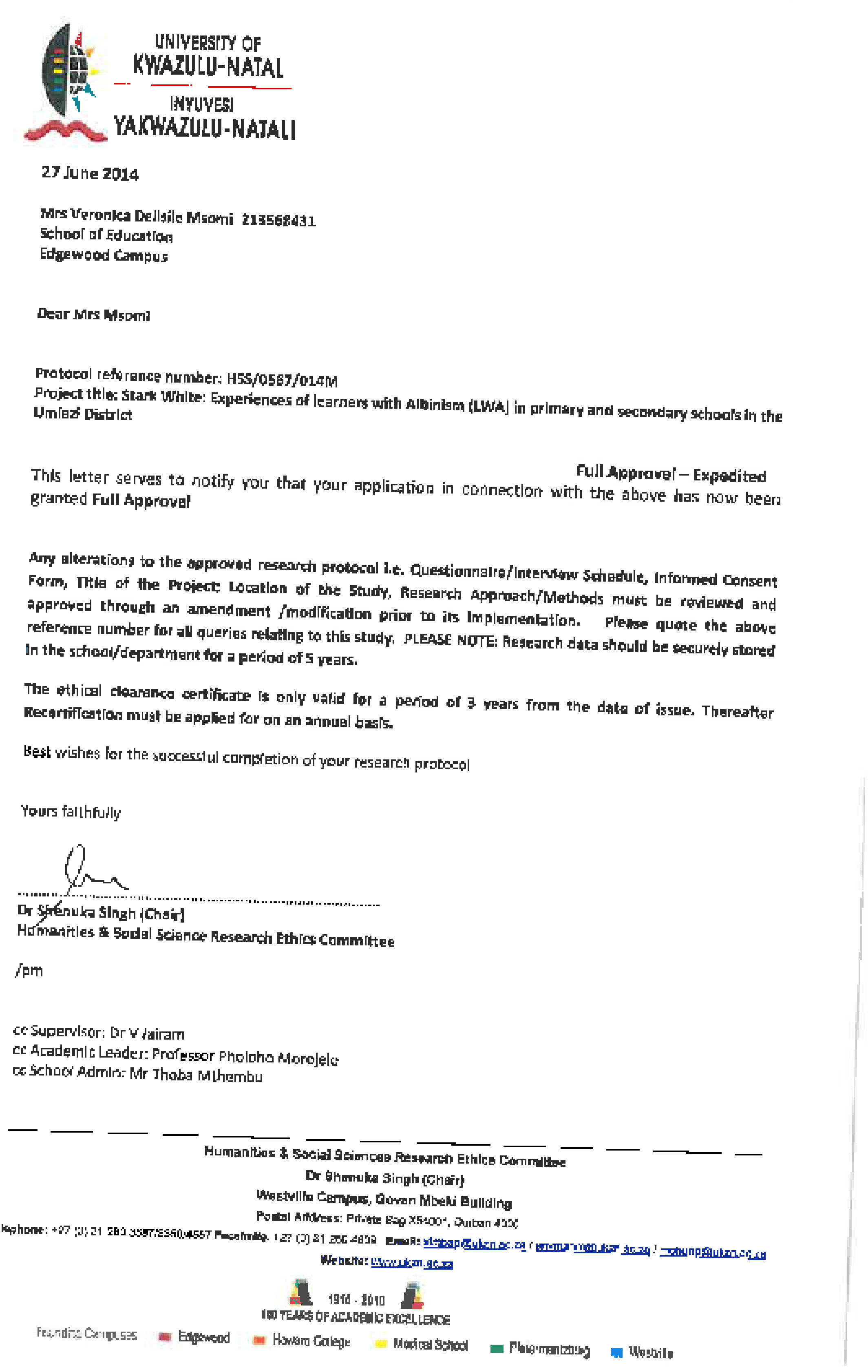
1. The researcher will make all the arrangements concerning the research and interviews.
2. The researcher must ensure that Educator and learning programmes are not interrupted.
3. Interviews are not conducted during the time of writing examinations in schools.
4. Learners, Educators, Schools and Institutions are not identifiable in any way from the results of the research.
5. A copy of this letter is submitted to District Managers, Principals and Heads of Institutions where the intended research and interviews are to be conducted.
6. The period of investigation is limited to the period from 01 September 2014 to 31 March 2015.
7. Your research and interviews will be limited to the schools you have proposed and approved by the Head of Department. Please note that Principals, Educators, Departmental Officials and Learners are under no obligation to participate or assist you in your investigation.
8. Should you wish to extend the period of your survey at the school(s), please contact Miss Connie Kehologile at the contact numbers below.
9. Upon completion of the research, a brief summary of the findings, recommendations or a full report / dissertation / thesis must be submitted to the research office of the Department. Please address it to The Office of the HOD, Private Bag X9137, Pietermaritzburg, 3200.
10. Please note that your research and interviews will be limited to schools and institutions in KwaZulu-Natal Department of Education (Umlazi District).

Nkosinathi S.P. Sishi, PhD
Head of Department: Education
Date: 15 September 2014

KWAZULU-NATAL DEPARTMENT OF EDUCATION

POSTAL: Private Bag X 9137, Pietermaritzburg, 3200, KwaZulu-Natal, Republic of South Africa ...dedicated to service and performance
PHYSICAL: 247 Burger Street, Anton Lembede House, Pietermaritzburg, 3201. Tel. 033 392 1004 beyond the call of duty
EMAIL ADDRESS: kehologile.connie@kzndoe.gov.za / Nomangisi.Ngubane@kzndoe.gov.za
CALL CENTRE: 0860 596 363; Fax: 033 392 1203 WEBSITE: WWW.kzneducation.gov.za

APPENDIX B



UNIVERSITY OF
KWAZULU-NATAL
INYUVESI
YAKWAZULU-NATALI

27 June 2014

Mrs Veronica Delisile Msomi 213568431
School of Education
Edgewood Campus

Dear Mrs Msomi

Protocol reference number: HSS/0567/014M
Project title: Stark White: Experiences of learners with **Albinism (LWA)** in primary and secondary schools in the **Umlazi District**

Full Approval – Expedited

This letter serves to notify you that your application in connection with the above has now been granted **Full Approval**

Any alterations to the approved research protocol i.e. Questionnaire/Interview Schedule, Informed Consent Form, Title of the Project, Location of the Study, Research Approach/Methods must be reviewed and approved through an amendment /modification prior to its implementation. Please quote the above reference number for all queries relating to this study. PLEASE NOTE: Research data should be securely stored in the school/department for a period of 5 years.

The ethical clearance certificate is only valid for a period of 3 years from the date of issue. Thereafter Recertification must be applied for on an annual basis.

Best wishes for the successful completion of your research protocol

Yours faithfully

....

Dr Shenuka Singh (Chair)
Humanities & Social Science Research Ethics Committee

/pm

cc Supervisor: Dr V Jairam
cc Academic Leader: Professor Pholoho Morojele
cc School Admin: Mr Thoba Mthembu

Humanities & Social Sciences Research Ethics Committee
Dr Shenuka Singh (Chair)
Westville Campus, Govan Mbeki Building
Postal Address: Private Bag X54001, Durban 4000
Telephone: +27 (0) 31 260 3587/8350/4557 **Facsimile:** +27 (0) 31 260 4609 **Email:** [illegible] / [illegible] / [illegible]
Website: www.ukzn.ac.za

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APPENDIX C

Social Sciences, College of Humanities,

University of KwaZulu-Natal,

Edgewood Campus,

The Principal

INFORMED CONSENT LETTER FOR THE GATE-KEEPER

My name is Veronica DelisileMsomi,I am a Masters in Educational Psychology candidate studying at the University of KwaZulu-Natal, Edgewood campus, South Africa.

I am interested in learning experiences of learners with albinism (LWA) in schools and how these learners navigate those experiences. Hopefully different navigation strategies other LWA use will be of benefit to otherswith a similar condition. To gather the information, I am interested in asking a learner in your school some questions.

Please note that:

- Your school’s confidentiality is guaranteed as your learner’s inputs will not be attributed to your schoolor your learner, but will be reported only as a population member opinion.
- The interview may last for about 1 hour and may be split depending on your learner’s preference.
- Any information given by your learner cannot be used against you or your school, and the collected data will be used for purposes of this research only.
- Data will be stored in secure storage and destroyed after 5 years.
- The research aims at knowing the experiences of LWA in school and how they navigate those experiences.
- Your learner’sinvolvement is purely for academic purposes only, and there are no financial benefits involved.
- If you are willing to let me interview your learner in your school, please fill the declaration part below.

I can be contacted at:

Email: delomsomi@yahoo.com

Cell: 0843220033

My supervisor is Dr. V. Jairamwho is located at the Department of Educational Psychology, Edgewood campus of the University of KwaZulu-Natal.

Contact details: email: jairam@ukzn.ac.za   Phone number: 0827700509.

DECLARATION

I……………………………………………………………………………(full names of principal) hereby confirm that I understand the contents of this document and the nature of the research project, and I consent tothis research project to take place in my school.

SIGNATURE OF THE PRINCIPAL **DATE**

…………………………… **……………………….**

SCHOOL STAMP

APPENDIX D

Social Sciences, College of Humanities,

University of KwaZulu-Natal,

Edgewood Campus,

Dear Parent/Guardian

INFORMED CONSENT LETTER

My name is Veronica Delisile Msomi,I am a Masters Educational Psychology candidate studying at the University of KwaZulu-Natal, Edgewood campus, South Africa.

I am interested in learning experiences of learners with albinism (LWA) in schools and how these learners navigate those experiences. Hopefully different navigation strategies other LWA use will be of benefit to your child as a participant and other learners living with this condition. To gather the information, I am interested in asking your child some questions.

Please note that:

- Your child's confidentiality is guaranteed as your child's inputs will not be attributed to your child in person, but reported only as a population member opinion.
- The interview may last for about 1 hour and may be split depending on your child's preference.
- Any information given by your child cannot be used against your child, and the collected data will be used for purposes of this research only.
- Data will be stored in secure storage and destroyed after 5 years.
- Your child has a choice to participate, not participate or stop participating in the research. Your child will not be penalized for taking such an action.
- The research aims at knowing the experiences of LWA in school and how they navigate those experiences.
- Your child's involvement is purely for academic purposes only, and there are no financial benefits involved.
- If you are willing to let your child be interviewed, please indicate (by ticking as applicable) whether or not you allow the interview to be recorded by the following equipment:

	willing	Not willing
Audio equipment		
Photographic equipment		

I can be contacted at:

Email: delomsomi@yahoo.com

Cell: 0843220033

My supervisor is Dr. V. Jairam who is located at the Department of Educational Psychology, Edgewood campus of the University of KwaZulu-Natal.

Contact details: email: jairam@ukzn.ac.za   Phone number: 0827700509.

Thank you for letting your child contribute to this research.

DECLARATION

I………………………………………………………………………(full names of parent) hereby confirm that I understand the contents of this document and the nature of the research project, and I consent to my child participating in the research project.

I understand that my child is at liberty to withdraw from the project at any time, should my child so desire.

SIGNATURE OF PARENT/GUARDIAN   DATE

APPENDIX E

Social Sciences, College of Humanities,

University of KwaZulu-Natal,

Edgewood Campus,

Dear Participant

INFORMED CONSENT LETTER

My name is Veronica Delisile Msomi, I am a Masters in Educational Psychology candidate studying at the University of KwaZulu-Natal, Edgewood campus, South Africa.

I am interested in learning experiences of learners with albinism (LWA) in schools and how these learners navigate those experiences. Hopefully different navigation strategies other LWA use will be of benefit to you as a participant and other learners living with this condition. To gather the information, I am interested in asking you some questions.

Please note that:

- Your confidentiality is guaranteed as your inputs will not be attributed to you in person, but reported only as a population member opinion.
- The interview may last for about 1 hour and may be split depending on your preference.
- Any information given by you cannot be used against you, and the collected data will be used for purposes of this research only.

- Data will be stored in secure storage and destroyed after 5 years.
- You have a choice to participate, not participate or stop participating in the research. You will not be penalized for taking such an action.
- The research aims at knowing the experiences of LWA in school and how they navigate those experiences.
- Your involvement is purely for academic purposes only, and there are no financial benefits involved.
- If you are willing to be interviewed, please indicate (by ticking as applicable) whether or not you are willing to allow the interview to be recorded by the following equipment:

	willing	Not willing
Audio equipment		
Photographic equipment		

I can be contacted at:

Email: delomsomi@yahoo.com

Cell: 0843220033

My supervisor is Dr. V. Jairam who is located at the Department of Educational Psychology, Edgewood campus of the University of KwaZulu-Natal.

Contact details: email: jairam@ukzn.ac.za   Phone number: 0827700509.This study is also ethically approved by the University of KwaZulu-Natal’s Human Social Sciences Research Ethics Committee.
The Research Office at Govan Mbeki Centre contact details:

Contact person: Prem Mohum

Tel: 031 2604557

Fax: 031 2604609

E-mail: mohunp@ukzn.ac.za

Thank you for your contribution to this research.

DECLARATION

I………………………………………………………………………… (full names of participant) hereby confirm that I understand the contents of this document and the nature of the research project, and I consent to participating in the research project.

I understand that I am at liberty to withdraw from the project at any time, should I so desire.

SIGNATURE OF PARTICIPANT
DATE

……………………… ……………………….

APPENDIX F

INTERVIEW SCHEDULE

TITTLE: STARK WHITE: EXPERIENCES OF LEARNERS WITH ALBINISM (LWA) IN PRIMARY AND SECONDARY SCHOOLS IN THE UMLAZI DISTRICT.

Interview with:---

Gender:-------------- Age:---------------- Contact no.:---------------------------------

Date of interview:---------------------------- Place:---

Interview conducted by:---

INTERVIEW QUESTIONS

1. **What was your school day like today?**
2. **Do you have friends here at school?**
   - **If “yes” what do you do together?**
   - **If “no” why?**
3. **Do you ever feel you are different from other learners?**
   - **If “yes” why?**
4. **Do you have difficulties coping with your work in class?**
   - **If “yes” what do you do to keep up with others?**
5. **Where do you sit in class? Why?**
6. **What has been the most exciting thing that you have done/happened to you here at school**

7. **What has been the worst thing to happen to you at school?**
    - **How did it make you feel?**
    - **How do you feel about it now…..are you over it?**
    - **What helped you through it?**

8. **What sporting activities do you take part in here at school?**

9. **How do you protect your skin on sunny days?**

10. **When you finished your primary schooling and had to come to this secondary school, were you anxious?**
    - **How was your first day?**

11. **What would you say to an anxious learner with your condition going to a secondary school for the first time?**

12. **Given a chance, what would you ask of your teachers and fellow learners.**

13. **Is there anything else you would like to ask or tell me about your school life?**

THE RADIO DRAMA – LOVE BUILDS

The main character in this radio drama is Madalo who is a nine-year-old girl with albinism. Madalo is living with her mother Mirriam. In a school that Madalo is enrolled in, she encounters discrimination and prejudice from her peers and her ignorant teacher who misinterpret Madalo’s eyesight problems for laziness and poor learning ability. Madalo ends up dropping out of school.

When a new teacher Mr. Zgambo joins the school, things started to change. With his LOVE for all the children and experience with learners who have different learning difficulties, he assists his fellow teachers and Madalo’s peers to understand challenges Madalo faces and their causes. This understanding results in Madalo coming back to school and enjoying her school life with the support from the teachers and her peers. LOVE BUILDS.

FOCUS-GROUP DISCUSSION SCHEDULE

TITTLE: STARK WHITE: EXPERIENCES OF LEARNERS WITH ALBINISM (LWA) INPRIMARY AND SECONDARY SCHOOLS IN THE UMLAZI DISTRICT.

QUESTIONS

1. If you were the learner with the skin condition in this radio drama, how would you have felt? **- Why?**
2. How would you have handled the situation? **- Why?**
3. What do you think about the way both the teacher and the principal handled the situation? **- Why?**

4. If you were one of the learners without albinism, what would you have said / done? **- Why?**
5. What is the worst thing that a teacher/learner ever did to you that embarrassed you in front of other learners? **- How did you handle the situation?**
6. What is the most memorable thing that a teacher/learner ever said to you that made you feel you really are one of their own? **- Why?**