

**Title: The social experiences and academic challenges faced by students with albinism
in the University of Limpopo**

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Declaration

With the submission of this mini-dissertation in Clinical Psychology I declare that the entirety of this work is my original work. I am the sole author thereof, unless otherwise stated. I have referenced all sources, and to my knowledge, have not plagiarised.

Signature _____ Date _____

ABSTRACT

Students with albinism experience social and academic challenges in society. These challenges are mainly influenced by their disability. Studies indicate that because they look different from most people they are treated differently and socially excluded and marginalised. Albino individual' are also murdered in South Africa which is motivated by myths, beliefs and misconceptions in traditional African societies. The Social Model of Disability (SMD) underpinned the study as it is used to explore social experiences in different life contexts. The study used a qualitative approach with an exploratory research design. Purposive sampling was used to select the 18 participants. Thematic Content Analysis (TCA) was used to analyse data collected from the three focus groups. The findings of the study revealed that the social experiences of students with albinism are be difficult. They experience discrimination and stigmatisation from their peers and are often called derogatory names. It was also found that students with albinism have academic challenges because of their impaired vision, lecturers' negative attitudes and insensitivity towards them. It was also found that the lack adequate assistive devices. Social experiences and academic challenges lead to a self-reported negative impact for instance, depression for these students. Ultimately, more awareness initiatives about the condition are required at the institution in order to improve the experiences of students with albinism.

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CHAPTER 1: INTRODUCTION

1.1 Introduction to the study

Albinism is a genetic condition that is widespread in the southern regions of Africa commonly affecting pigmentation of the skin, hair and eyes (Lund, 2001). According to Lund and Lynch (2013, p.183), “albinism is found in all populations but has a relatively high frequency throughout Sub-Saharan Africa, with a prevalence of 1 in every 3900 persons.” It is characterised by little or no pigment in the skin and hair, and other physical or medical problems (Lund, 2001).

Salewi (2011) indicates that albinism is usually regarded as a disability in African societies, and as such, invites negative social attitudes that are characterised by lack of understanding, fear and prejudice. The condition is accompanied by many physical health problems (for instance, heart disease) which can lead to many educational and social adjustment problems. According to Baker, Lund, Taylor and Nyathi (2010), poor vision is a problem associated with albinism that precipitates problems in day-to-day living.

According to Thuku (2011), in most societies across the world albinism is a condition that is misunderstood and surrounded by unfounded myths. These misconceptions result in people with albinism having many life challenges. Additionally, children with albinism find themselves hidden from the public and forbidden from socialising with others. They are often treated as social outcasts.

Albinism is a condition which results in many people in Africa, with the genetic disorder, being excluded from education and employment thus many live in poverty (Baker et al., 2010). Children and young people with albinism are doubly vulnerable, their striking physical difference, (looking ‘white’ in a black population) makes them a target for bullies (Lund & Lynch, 2013).

1.2 Research problem

Albinism is a condition that cannot be cured (Salewi, 2011). It is a disorder that is accompanied by many health problems such as visual impairment (which can rarely be corrected by optometric measures) and ultraviolet induced skin damage. Furthermore, harsh conditions, such as direct exposure to sunlight and limited access to quality health care systems, means that those affected rarely get the help they need. According to Baker et al. (2010), these problems lead to people with albinism facing many different kinds of social

maladjustment, including discrimination, psychological disorders, physical assault and even murder. In South Africa, albinism is more common in the Southern Sotho and Tswana ethnic groups as compared to the Nguni ethnic groups (Pooe-Monyemore, Mavundla, & Christiansen, 2011). There are myths surrounding albinism that are associated with birth, life and death with many traditional African families perceiving it as punishment from the Gods (Selepe, 2007).

Baker et al. (2010), postulate that social and academic adjustment problems can affect the employment rate of people with albinism. Additionally, the authors suggest that the segregation of people with albinism begins early in their lives as they are not always allowed to attend school. This may be because they do not have access to proper skin creams that protect them from the sun or because they are discriminated against.

Black individuals affected with albinism in South Africa have many problems associated with social adjustment because of discrimination (Manga et al., 2013). Measures to ensure that pupils with albinism adjust well socially and academically have been proposed (Salewi, 2011). However, little research has been conducted in the context of higher institutions of learning. This study aims to fill that gap as it seeks to investigate the social and academic challenges faced by students with albinism registered at the University of Limpopo.

1.3 Operational definitions

1.3.1 Albinism - In this study the term ‘albinism’ refers to a condition that is characterised by little or no pigmentation in the skin, hair and eyes which can result in a variety of health problems (Lund, 2001).

1.3.2 Social experience – In this study social experience is operationalised as something that happens to an individual, in a social setting, that affects how they feel (Merriam-Webster, 2008).

1.3.3 Academic challenge – This is operationalised as any difficulty in an academic realm which means an individual will have difficulties meeting academic requirements (Merriam-Webster, 2008).

1.4 Purpose of the study

1.4.1 Aim

The aim of the study is to explore the social experiences and academic challenges that are faced by students with albinism at the University of Limpopo.

1.4.2 Objectives

- a) To examine the social experiences of students with albinism registered at the University of Limpopo.
- b) To investigate the academic challenges encountered by students with albinism registered at the University of Limpopo.
- c) To explore environmental dynamics that lead to social and academic difficulties faced by students with albinism at the University of Limpopo.

1.5 Significance of the study

The study sheds light on the social experiences and academic challenges of students with albinism registered at the University of Limpopo. The findings will be given to the Director of the Reakgona Disability Centre (commonly referred to as DSU) so that any interventions (if needed) can be made. Moreover, the research will help maximise the psychological health of students with albinism by providing an insight into the social and academic impact of their disorder in a university context.

1.6 Breakdown of chapters

- Chapter 1: provides an introduction of the paper as well as an outline of the research question, objectives and the importance of the study.
- Chapter 2: reviews relevant literature based on similar studies conducted on experiences associated with albinism. It provides support and aligns the study with similar work that has already been done.
- Chapter 3: illustrates the theoretical framework of which the study is based on. It also relates the theory or model to the research problem.
- Chapter 4: illustrates the methodology that the study is going to follow. It describes the sample of participants in the study as well as how data will be collected from the sample of participants and analysed.
- Chapter 5: presents the findings of the study including the themes extracted from the participants' responses. It also concludes the study and provides the recommendations.

1.7 Summary

This chapter introduced the research noting the study aims and objectives, the research problem, its purpose, operational definitions and significance. The following chapter gives an overview of recent and older literature pertaining to the topic.

CHAPTER 2: LITERATURE REVIEW

2.1 Introduction

In this chapter a broad overview of literature which includes books, theses, dissertations and journal articles is given to provide a background to the investigation.

2.2 The nature of albinism

Albinism is a genetic condition in which a person lacks the gene for producing melanin which is the pigment that protects the skin from ultraviolet (UV) light (Thuku, 2011). Melanin shields the skin from ultraviolet radiation (Manga, Kerr, Ramsay & Kromberg, 2013). The melanin is also responsible for the color of the skin, hair and eyes. Those affected have little pigment in the hair, skin and eyes, in sharp contrast to normal pigmentation (Lund, 2001). Deficiencies associated with this lack of pigmentation are also accompanied by various physical, social and psychological health problems.

The United Nations Human Rights Council (UNHRC, 2016, p.5) distinguishes the different types of albinism as follows:

“The most common and visible type is oculocutaneous albinism (OCA), which affects the skin, the hair and the eyes. Within this type, there are subtypes, which reflect varying degrees of melanin pigment deficiency in an individual. The main subtypes of OCA are tyrosinase negative albinism (OCA1) and tyrosinase positive albinism (OCA2). In OCA1, there is little or no production of melanin and it is often characterized by white hair and opaque or transparent irises. In the more prevalent, particularly in African countries, OCA2, some melanin is produced and it is characterized by yellow-blond or sandy-coloured hair and grey to light brown irises. A less common form of albinism is ocular albinism which affects the eyes alone, while albinism accompanied by Hermansky-Pudlak syndrome is another less common form, which is characterized by bleeding disorders, bowel (colitis) and lung diseases”

Pooe-Monyemore et al. (2011), also report that because of the lack of, or minimal production of melanin, people with ocular-acute albinism suffer from various physical and physiological conditions, including severely sensitive skin and increased risk of skin cancer caused by excessive sun exposure. The problems related to living with albinism in Southern Africa are

vast. People with albinism are more vulnerable to an increased risk of developing skin cancer due to sunburns and long-term skin damage.

The condition is inherited through the autosomal recessive gene, which implies that a person with albinism inherits two defective genes, one from each parent (Pooe-Monyemore, 2007). According to Manga et al. (2013), the mutations in the set of autosomal recessive genes are described as a consequence of failure to deliver protein to the melanosome. These mutations in the genes results in at least nine forms of the condition that have been described so far.

Albinism can affect any race, it is found throughout the world. However, the number of people with albinism globally is uncertain. It is estimated that 1 in 17000 people will be born with the condition and that it is more prevalent in some parts of the world than others (Thuku, 2011). For instance, the condition is more prevalent in sub-Saharan Africa than anywhere else in the world. Prevalence is as high as 1 in 18 000 to 20 000 people in the United States of America (USA) but it can be as high as 1 in 4 000. In South Africa it is estimated that one in every 3900 persons has the condition (National Organisation for Albinism and Hypopigmentation [NOAH, 2014]).

Albinism has no cure but when it is properly managed people affected by this condition can live a long and relatively healthy life (Salewi, 2011). According to NOAH (2014) , people with albinism may adapt to their condition by learning how to perform various activities including reading, driving, riding bikes and fishing, even though their visual acuity is usually low at 20/200 or worse.

2.3 Social maladjustment associated with albinism

According to Under the Same Sun (UTSS, 2014), colourism is like racism, in other words ethnic African groups who suffered from albinism were discriminated against. This discrimination still exists however, there is a growing awareness that lighter coloured or white coloured or ‘colourless’ individuals have a genetic illness which is heredity. It is also true that Caucasians who suffer from albinism in South Africa also experience discrimination because they are considered ‘too white’ among their own ethnic group.

Mswela and Nöthling-Slabbert (2013) state that colour and race are inextricably linked however, in albinism, colour and race are not related. People living with albinism, whatever their ethnic group, are normally subjected to discrimination, stigma and bias based on their ‘whiteness’ alone. Their excessive ‘whiteness’ is often associated with witchcraft or the devil’s work and other negative connotations whatever their ethnic group.

Perceptions about people with albinism are not only centered around negative attitudes and negative perceptions that are associated with the condition, some people believe that they have supernatural powers. According to UTSS (2014), these include the belief that people with albinism are ghosts and that they never die. It is also believed that sexual intercourse with people with the condition can cure HIV/AIDS which leads to sexual violence (rape). There is also the belief that if the genitals of people with albinism are used in traditional practices that the medicine or *muti* (made out of them) can bring wealth and good luck when consumed in potions (or worn as amulets).

There are also records of infanticides, where albino babies have been murdered by their parents, family members and/or members of their communities. According to Phatoli, Bila and Ross (2015) people with albinism live in constant fear of being hunted for their body parts. Another belief is that if an individual marries a person with albinism they will be successful in life, thus they marry an albino which can lead to unhappy marriage and verbal, physical or sexual abuse (of the albino person). However, there is another belief that surrounds marriage to people with albinism. Many communities believe that albinos are not suitable for so-called 'normal' people thus marriage to an albino can result in them being ostracised by their communities (and sometimes their families).

People with albinism also have a barrier as far as participating in social events in their own communities is concerned. In a study conducted in Botswana, it was reported that children believe that albinos are 'from the devil' and resort to spitting on their clothes and throwing stones at them (Dart, Nkanotsang, Chizwe, & Kowa, 2010). This means that albinos generally avoid social situations.

Miles (2011) conducted a study in Zambia where the teacher of a boy with albinism reported that she feared having a student with albinism in her class. The teacher stated that she feared the sores on his hands which were as a result of sunburn, but she did not understand this. She believed that whenever she saw an albino she had to spit on her chest (otherwise she would be cursed). This further shows how the lack of understanding and the perpetuation of myths in communities facilitates the exclusion of people with albinism.

Mswela (2016) states that being isolated or treated differently from others often leads to people with albinism having a lack of self-confidence and lack of self-esteem. People who live with albinism which is often describe by many as 'fair tanned,' live with discrimination as it has many negative social implications. Albinos have to try and function in a society

which treats them differently from people with a 'normal' amount of melanin in their skin (Palmer, 2007). An environment that shuns people with albinism has a negative impact on their self-esteem. According to (NOAH, 2014), Parents can help their albino children cope with discrimination by encouraging them to share their experiences and feelings about their condition.

Masanja, Mvena and Kayunze (2014) report that in Africa, many people suffer from albinism. They are perceived as different from those that surround them in society as they have white skins but are ethnically designated as Black Africans. According to Phatoli et al. (2015), although most people with albinism tend to have light hair, skin and eyes they still have African features and hair texture. In Western societies, with predominantly light pale-skinned populations, people with albinism can pass unnoticed however, in sub-Saharan Africa it is the most visible of conditions (Baker, Lund, Taylor, & Nyathi, 2010).

People with albinism have reduced access to opportunities and social participation because of the stigma that surrounds them (Ndomondo, 2015). According to Ntinda (2009), cultural practices and superstitions add to the stigmatisation and discrimination against people with albinism. Problems associated with the condition such as low visual acuity and the high risk of skin cancer increases the possibility of discrimination, stigma and bullying (Burke, 2012).

Salewi (2011) reports that people with albinism are vulnerable to attacks and violence from their peers, other members of the community and even family members. Many people who believe that the bodies and limbs of people with albinism may be supernatural as a way to generate income. In addition, Tanzania and some other parts of Africa have been subjected to brutal attacks and murders because people with albinism have been associated with African beliefs of witchcraft and malice. (Burke et al., 2014)

Children and young people with albinism, in an educational environment, are disadvantaged and vulnerable in different ways. Lund and Gaigher (2002) state that the physical health problems, psycho-social difficulties and lack of acceptance by peer groups cause endless problems in terms of their social experience in an educational environment (Burke, 2012). This causes significant difficulties such as lack of, or poor access to, education and consequently puts them in a difficult position when they seek employment.

According to Cross (2009), most people with albinism who are in paid employment which is a small proportion of the total population are most likely to find employment outdoors in the scorching sun where their skins are vulnerable to burns. This involves activities like roadside

trading, market stalls, agricultural day-labour and the like. Those who are not in paid employment survive by tending small plots where they are still exposed to the harsh sun burns.

2.4 Social experiences of students with albinism

In their study undertaken at a South African university, Phatoli et al. (2015) found that students with albinism have to continually convince themselves that they are normal because of the negative reactions they receive from their peers. Students with albinism recognise that this is due to their peers' lack of knowledge about the condition but they still feel hurt and rejected. Name calling, as a form of bullying, is a common experience, which students with albinism have to endure (Selepe, 2007).

Selepe (2007) recognises that external forces are more likely to play a major role in shaping self-esteem for people with albinism, in that children with albinism brought up in an environment where they are considered and treated as stereotypes, not individuals in their own right. Consequently, social reaction determines the intra-personal confidence of albinos and, if it is negative, it is likely to result in them having low self-confidence (Msomi, 2014).

National Organisation for Albinism and Hypopigmentation [NOAH] (2014), report that students with albinism face the challenge of name calling and bullying during their school years. This kind of teasing can cause psychological damage as the albino person who is teased will not be able to have a positive self-reflection and thus are likely to have accepted their condition. Furthermore, Selepe (2007) states that even affectionate teasing can cause emotional hurt (Selepe, 2007). According to Ndomondo (2015), the attitude of others towards albinism is critical if family members and peers accept them, they do well in academic and social spheres.

Research by Msomi (2014) supports findings of Pooe - Monyemore et al. (2012) and Lund and Gaigher (2002) in a study conducted in Gauteng Province. The author found that the majority of students with albinism were of the view that the problems they experienced at school were more of a social than an educational nature. According to their findings the lack of social interaction perpetuates discrimination and bullying as albino children become isolated and do not get the social interaction they need. This usually delays their development socially and academically.

One of the problems associated with discrimination in terms of disability is that there is often no policy pertaining to bullying in schools. If a policy does exist, it is often inadequate,

because bullying often remains unnoticed by school teachers and administrators (Padmore, 2005). The social experiences of students with albinism may ultimately depend on the understanding and beliefs that their peers hold in terms of albinism.

Padmore (2005) states that physical differences, that can be seen, increase the cases of bullying. As a result, students with albinism are more likely to have problems with learning due to: a) not wanting to attend school because of bullying and b) not being able to see teaching aids due to poor visual acuity. One study reported that a small percentage of students with albinism found it easier to make friends with peers, who were not albinos however, most reported having friends that also have the condition (Phatoli et al., 2015). All students with albinism in South Africa reported experiencing loneliness and non-inclusion in social activities by their peers because of their condition (Matshovhana & Mulibana, 2014).

However, it must be recognized that some people who have the condition do not see themselves as disabled, nonetheless, they are offended by their peers' reaction to their condition. (Padmore, 2005). Students with albinism in general education schools also experience psychological bullying by their peers and teachers for instance, students with albinism at Univen reported that other students do not sit near them in the classrooms and avoid them at university events (Baker et al., 2010).

Baker et al. (2010), report the case of a Zimbabwean woman whose daughter's pregnant teacher placed her albino daughter at the back of the class. As a result, the child could not see what was on the blackboard which lead to a poor academic performance. The teacher believed in negative myths about albinos and thought her unborn child might suffer some evil if the child was seated to close to her. Msomi (2014) states that the negative attitude of others are an important barrier to learning and the general well-being of students with albinism which happens when their peers and teachers stigmatise them.

Generally, people with albinism, due to their photophobia, have visual problems not only in strong sunlight but also in moderately lighted areas. This problem contributes to the sometimes abnormal, appearance of their faces. In addition, students with albinism usually read, keeping objects (such as books and cell phones), very close to their faces. This is due to their visual impairment, but it can seem very strange to other students (UTSS, 2014).

2.5 Albinism and academic challenges

Social, economic, occupational and educational exclusion is a major problem for people with albinism (Lipson & Rogers, 2000). According to Baker et al. (2010), people with albinism are

often subject to substandard living and working conditions and many are excluded, because of the way they look, from the workplace. Salewi (2011) asserts that physical violence, towards people with albinism in Tanzania, creates a barrier that denies them educational opportunities and access to other social services.

Mswela (2017) reports that the brutal attacks and murders of children with albinism significantly limited their freedom of movement. For instance, some pupils with albinism stopped attending school because of fear for their own security. Lund and Lynch (2013) also report that alarming evidence has come to the fore in that some children with albinism do not attend school because of intimidation, bullying and violence from their peers, little understanding from teachers and insufficient parental support. They further reported that attitudes to including students with visual impairments in mainstream education was, by the school bodies, generally supportive but that this support did not 'trickle down' to teachers or students.

Lund (2001) revealed evidence that some children with albinism in rural areas do not attend school because of bullying. There was also evidence of gender inequality, with twice as many boys (as compared to girls) with albinism being able to attend some form of educational activity. According to Ndomondo (2015), teachers, lecturers and educational supervisors lack knowledge about the learning needs of people with albinism. They are unaware of the physical, social and psychological support needed by people who have the condition. For instance, people with albinism often do not have access to medical doctors, counselling and optical devices needed for educational purposes.

Kiishweko (2017) reports that some of the barriers that are faced by disabled students including students with albinism in higher learning institutions include poor teaching and learning resources, negative attitudes, ignorance and prejudice as well as limited access to the learning and teaching resources (in the case of students with albinism visual requirements are often not catered for). These students particularly those who are enrolled in mainstream education may be forced to use the same resources as their peers which are not well suited for their educational needs.

In a study by Lund and Lynch (2013) indicate that in Malawi for instance, there are residential centres that accommodate students with visual impairment. There are 14 elementary schools and 15 secondary schools as well as 7 higher education institutions in the country. They perform an important function in the education of blind students and those who

have poor eyesight, including people with albinism. Many of these centres have an excessively high student-teacher/lecturer ratio (1:30) and many of the facilities urgently need repair and reconstruction, (especially in the primary sector). Not many higher education institutions in Africa are able to support blind or partially sighted students. In a study at the University of Limpopo (South Africa), Mashau (2012) found that students were able to cope with mainstream education if there are appropriate interventions implemented to help them manage problems associated with albinism such as visual acuity as well as skin vulnerability. This is one of the few (or only) higher education institutions in the country that caters for those who are blind or have poor visual acuity.

Problems of vision have been recognised as a major aspect in disabilities that affect student progress in terms of education. This is not only because of blindness but because people with albinism have little melanin they are extremely sensitive to sunburn. This creates a great challenge as they find it difficult walking to classes or taking part in outdoor recreational activities (most institutions do not supply sun blocks) which are needed by people with albinism (Matshovhana & Mulibana, 2014).

Many institutions or schools do not have proper access for students with albinism who could for instance, be injured by falling especially in the bright sunlight as they cannot see steps especially on a sunny day (as their vision is more impaired). Sunglasses must be prescribed and many students do not have access to medical aids or money for this. Some institutions have upper levelled classrooms, and students with albinism take more time climbing stairs and sometimes cannot find rails that will help them (even if they exist). These problems intensify when they are in the classroom as they often cannot see texts are used (Msomi, 2014).

The few special schools that accommodate students with albinism do not cater to their needs and are not best designed for their needs as the teachers are also not specifically trained for the task (Msomi, 2014). Dart et al. (2010), report that students with albinism perform poorly in many subjects, which is mostly due to their poor visual acuity.

There are several special schools in South Africa offering adapted educational systems for blind and partially blind students, most of whom are students with albinism. These schools are designed primarily for students with poor eyesight and are specially adapted to reduce brightness, with shutters on the windows on one side, and covered walkways on the other. Rooms are equipped with mobile blackboards on wheels, which can be moved to the best

place at different times of the day (Selepe, 2007). The author notes that in this type of school's students with albinism do well and generally achieve academic success some are even able to go on to tertiary education. In South Africa albino students who have eyesight problems often do not have the physical and emotional support they need for instance, counselling, specialised optical devices and textbooks and ergonomically designed buildings. Many schools do not have desks or enough classrooms for children to sit in on the African continent (Ndomondo, 2015). According to a Non-Governmental report (NGO report (UTSS, 2014), there is also a marked lack of educational systems that takes into account the visual disability of children with albinism.

In a school situation, students with albinism often hesitate to read around other students, because they have to bring the reading material closer to their eyes. Obviously, students with albinism at school may experience double stigma due to skin colour and visual impairment. These challenges are likely to immediately cause a negative evaluation by others. Students with albinism are discriminated and stigmatised against by their peers and teachers (Msomi, 2014; Ntinda, 2009). Ntinda (2009) reports that among many forms of discrimination children with albinism come across includes how teachers mistreat them based on the color of their skin.

South Africa is more accommodating than most African countries in the sub-Saharan region. According to Baker et al. (2010), in South Africa, students with albinism are likely to attend special school which makes some effort to facilitate integration, however in Zimbabwe and many other African countries students attend mainstream school (with no effort made to accommodate them) where they face difficulties (Msomi 2014; Selepe, 2007). However, in some mainstream schools teachers, realise that albino students have visual problems and sit them close to the blackboard in class ensure that they are able to see which improves their academic success. This has a negative connotation however, as their peers think they are seated close to the board because they are 'stupid' (Cross, 2009).

Matshovhana and Mulibana (2014) report that in a study conducted in a special school in Limpopo Province in South Africa, it was reported that parents encourage children with disabilities such as albinism to participate in recreational and sports activities. This facilitates the integration of albino students and increases acceptance from their peers which encourages their positive self-esteem and confidence. These two characteristics are important to academic and social success.

2.6 Albinism in the global sphere

As people in western societies are predominantly white population, people with albinism often remain unnoticed however, in sub-Saharan Africa it is a very visible condition (Baker et al., 2010). It has a particularly high prevalence in sub-Saharan Africa and in South America. Albinism, although a relatively rare condition, occurs in all races. This means that the condition is often known, but not understood (UTSS, 2014). Discrimination can occur because of the false beliefs and mysticism pertaining to albinism influenced by negative cultural attitudes and practices. This is because people do not understand the condition that they tend have attitudes of fear and attitude that involve these false beliefs.

According to UTSS (2014), the nature and consequences of the stigma faced by the people with albinism differs in the various regions around the world, depending on the effectiveness of domestic human rights laws. For example, in North America, where human rights are generally normalized, there are no records of physical attacks on people with albinism. However, in aspects of life that often go beyond ordinary justice, people with albinism suffers greatly. These include the aggressive challenge of the name calling, persistent agitation among peers, intimidation and constant demonization and fears of people with albinism in pop culture, especially in literature and film.

In North America and Europe, it is estimated that 1 out of 17,000 to 20,000 people are affected by albinism. Msomi (2014) reports that the prevalence of albinism differs from one country to another. It is estimated that in the United States of America, 1 person out of 17,000 has a albinism, Norway has a prevalence of 1 to 9650, and Northern Ireland, 1 to 10 000. Dart et al. (2010), report that other studies show that in some groups in Panama and the Pacific, the rate of decline can be up to 1 in 70 to 125 people.

Albinism affects people from all races, the frequency of albinism in global populations generally is about 1 in 17000. The prevalence of albinism is the least among people of Asian descent. According to UTSS (2014), in North America and Europe, approximately 1 in 20.000 people has albinism

Importantly Jenkins (1982), reports that oculocutaneous albinism is more common among the South African Black population than among the White population in Europe. This

background has caused the need to study the life experience of people with oculocutaneous albinism in Black population in South Africa (Pooe – Monyemore et al., 2012).

In India, people with albinism are subjected to the same stigma and beliefs as other parts of the world. According to UNHRC (2015), there are reports from Mumbai, India, that also point out that people with albinism are generally considered to be damned and/or cursed. Their ‘curse’ is viewed as contagious and they are marginalised and ostracised from society because of their appearance.

According Wan (2003), in Canada, students with albinism are called ‘Whitey,’ ‘Powder,’ ‘Ghost’ and ‘Casper’. In Malawi, Braathen and Ingstad (2006) found that albino persons are called *Mzungu* (white man), *Zigoma* (the name of the famous gospel singer with albinism) and *Napwere* (a very wrinkly light brown pea). Nowhere is this clearer than the common names used for albino’s worldwide names such as *Goddess of water*, *pig*, *monkey*, *immature banana* and *money* (referring to the myth that if an individual marries an albino he or she will become rich). Society defines what it means to be human and when a group is defined as something less than human acts of discrimination become acceptable (UTSS, 2014).

Cases seem to differ however in different regions thus people with albinism are likely to have different experiences in different countries. Anti -discrimination laws in Australia protect the rights of people with albinism. In Canada and the USA, people with albinism are considered ‘legally blind’ and thus their disability status is well protected and they appear to suffer less discrimination than in Africa (Msomi, 2014).

2.7 The occurrence of albinism in Africa

According to Dart et al. (2010), many people with albinism in a number of sub-Saharan countries can be described living in a life-threatening situation. This leads to their segregation within their own communities (Salewi, 2011). In sub-Saharan Africa it may affect 1 per 5,000-15,000, with certain countries with a much greater frequency, including about 1 in 1,400 and approximately 1 in 20 in the general population bearing the gene for albinism. According to Kiishweko (2017), albinism is a genetically inherited condition, and it affects all people ethnic backgrounds all over the world. In Tanzania, this stage affects each of 1,400 people.

According to Thuku (2011), people with albinism in Tanzania often face social discrimination, prejudices, and biases, including the threat of murder as there are myths

which commoditise their body parts (thus some people pay money for them). In most cases attackers dismember parts of the albinos' bodies for instance, fingers, arms, legs, eyes, genital organs, skin, bones, head and hair which are used for traditional rituals (Dart et al., 2010). Because of false representations and myths, people with albinism in many parts of Africa are faced with discrimination from birth to death. Baker et al. (2010), report that living with albinism in Africa is dangerous physically and psychologically. These myths occur as a result of communities not understanding the genetic component of the condition and resorting to 'other' explanations (through lack of knowledge). Poverty in Africa may increase the life-threatening experiences that people with albinism have to endure when compared to other parts of the world. Commenting on the troubles of poverty and higher education in Africa, Kiishweko (2017) states that poverty can limit opportunities for pupils with albinism increasing the risk that they will continue to live in poverty.

Sexual abuse of people with albinism is common in Southern-African countries, including Zimbabwe, Swaziland and South Africa. Ceremonial desecration and rape of girls with albinism and women is very common (Nzelwa, 2016). The author suggests that a number of sub-Saharan African countries, including Zimbabwe, Swaziland, South Africa and Tanzania, continue to suffer from ritual abuse and rape of albino girls and women because of the strong traditional conviction that their body parts have magical and curative powers (such as healing HIV/AIDS).

According to the UNHRC (2015), women and children with albinism are particularly vulnerable because they are subject to cross-border attacks in the region and diverse forms of discrimination. It is noted that albino infants and children are often targeted for ritual murders while women with albinism are often victims of sexual violence (Phatoli et al., 2015). These beliefs worsen the social experiences of people with the condition in African countries in that they live in fear brought by community beliefs and myths about them. In fact, some children with albinism are hidden from the public or forbidden to interact with other people from a young age, because they are treated by the community as outcasts (Salewi, 2011).

Masanja et al. (2014), indicate that most people with albinism in Africa die at an early age or early middle age, they seldom reach old age. This is because of the comorbid medical conditions they have, which are often not treated, but also as a result of violent deaths perpetuated by members of their own communities. This puts albinos in Africa at greater risk of early mortality than those who live on other continents. It is also true that in Africa albino

children who have been abandoned are taken to shelters, residential schools or centres built for other needs (for example leprosy shelters). This is problematic because these shelters or schools have not been designed or equipped to meet their needs (Msomi, 2014).

According to Kiishweko (2017), the educational rights of albino children in Tanzania are often ignored as it was found that many of them were not a part of the education system. Additionally, the author states that in most African countries people with albinism remain excluded from education and employment and struggle to find housing. Poverty and the lack of health and social security structures further aggravate the situation, often putting all of the burden of care and education on the family (Baker et al., 2010). A study that was conducted in seven areas of Tanzania indicated that of the 178 children with albinism in these regions, 103 of them did not attend school. This is a poor indictment on the education system in the country (Kiishweko, 2017).

All forms of discrimination affecting people with albinism are interconnected, and there is an inextricable link between discrimination and poverty. For example, the right to education for individuals with albinism adversely affects the deterioration of their suffering. Low education, in turn, affects their right to an adequate standard of living experienced by many people with albinism to poverty. As a result, economic and social rights people with albinism disproportionately affect various types (UNHRC, 2016)

Discrimination violates albinos' basic human rights and fundamental freedoms however, this is the experience of the majority of albinos in Africa (Thuku, 2011). Common cases of violation of human rights includes killings, sexual abuse, educational and occupational exclusion. Traditional African beliefs and cultural attitudes towards people with albinism and their families contribute to their social exclusion (Nzelwa, 2016). Thuku (2011, p.3) reports the following African myths surrounding 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 though 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 impairment⁹. 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: Those 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.

2.8 Albinism in the South African context

According to Mswela (2016), people with albinism in South Africa do not encounter as much violent crimes as those in other African countries. The author reports that even though the incidents do not seem as extreme, they do show problems that are common throughout sub-Saharan Africa including harvesting of body parts for ritual practices as well as rape based on cultural myths.

Phatoli et al. (2015), report that a high prevalence of albinism in South Africa occurs in both urban, peri-urban and rural communities. A prevalence of 1 in 1 515 was recorded in study of congenital anomalies of new-borns in Sovenga, Polokwane, Limpopo Province, South Africa. This is higher than the overall national prevalence of 1 in 3 900 albino births. Furthermore, albinism occurs more often among Black ethnic groups than White, Coloured or Indian/Asian groups. These estimates compared to general prevalence in Africa indicates that South Africa, and Limpopo Province in-particular has the highest prevalence on the continent.

According to Jenkins (1982), as early as the nineteen eighties reported a high prevalence of albinism in the southern Sotho population which is mostly constituted of the Tswana people. The prevalence is much lower in the South African Bantu people (for example, 1 to 4 000, Xhosa, and 1 in 9 700 in the Pedi population. In the Shanghaan population 1 in 2 861 are born with albinism as compared to the Tswana group residing in Botswana who have a prevalence of 1 in 2 254.

According to Msomi (2014), the myths in South Africa around albinism affect students very negatively during their tertiary years and thereafter. Mswela (2016) reports that people with albinism experience violent physical attacks and live in constant fear for their safety. Many studies report that people with albinism drop out of school because of the negative attitudes of most of the communities they live in. Furthermore, Msomi (2014) states that South African students with albinism are often ridiculed with some reporting that they have been verbally abused being called names such as, *inkawu yasendlini* (house monkey), *isishawa* (the punished one), *umlungu* (derogatory name for a white person), *isphiwo* (gift, as in a gift that

can do something good for another), *cebile* (wealthy) and *ilawu* (a light-skinned person, not stated in a complimentary manner).

Mswela and Slabbert (2013) state that differences in skin colour have been a problem for the South African community as evidenced by racial segregation which is linked to the difficult history of the country (colonialism, separate development and later apartheid). They contend however, that people who live with albinism do not suffer discrimination, stigma and a biased attitudes based on colour alone, but suggest that their striking paleness of skin is associated with notions of mischief such as witchcraft which elicits generally negative responses from both white and black communities.

According to Selepe (2007), Myths about poor visual acuity in albinos in South Africa is associated with negative beliefs about birth, life and death. For instance, it is a punishment from the Gods which occurs during conception because the pregnant woman has experienced a traumatic event. One myth suggests that women who eat too much during their pregnancy may also bear an albino child. These myths are linked to stigma, bias and negative cultural beliefs in many traditional communities.

Thuku (2011) suggests that negative stigma is attached to albinism and other populations that are seen as 'different' within any given community. The author states that in general, albinism is associated with, and categorised as a blemish, mark, stain and disfigurement. That is, it is a visual stigma which communities regard with suspicion and fear.

Additionally, Thuku (2011) reports that the government in South Africa provides sunscreen from SPF 15 free of charge through regional hospitals however, many albino persons are not aware of this (or cannot access the clinics and/or hospitals where they can obtain the sunscreen). As a result, many people with albinism exhibit skin damage. Although most wear hats (and sometimes sunglasses to protect their eyes from the glare) these often only protect the upper part of the face, leaving the lower face and neck susceptible to sunburn. This is problematic as albino skin lacks melanin and, when exposed to the sun over a period of time, is prone to melanoma (skin cancer) which can be fatal.

2.9 Summary

The literature review provided an overview of the condition and recent and older literature on albinism. The following chapter provides the theoretical framework for the study.

CHAPTER 3: THEORETICAL FRAMEWORK

3.1 Introduction

The following chapter clarifies the theoretical framework that underpins the present research.

3.2 The Social Model of Disability (SMD)

According to Bailey, Harris and Simpson (2015), the difficulties that disabled people face are not disadvantages caused by their impairments for instance, physical and intellectual deficits, but the attitudes of society that can result in their exclusion from day-to-day social interaction. Furthermore, in addition to recognisable physical barriers, people with disabilities are exposed to subtler forms of discrimination in society including negative attitudes, beliefs and behaviours related to their impairments.

It is a specific community or society that turns against people with physical disabilities. Disability is something that people cannot help, it is not of their own doing however, as a result they are mostly isolated and excluded from full participation in society. Consequently, the disabled are an oppressed group in many societies. To understand this, we must understand the distinction between physical disabilities and the social condition referred to as a disability. According to Bampi, Guilhem and Alves (2010), the Social Model of Disability (SMD) was structured in contradiction to the Medical Model of Disability (MMD). The latter model suggests that disability is related to defeat (people cannot cope with their state in life) and illness or physical constraints which are the main cause of social inequality and disadvantaged experiences. This ignores the role of social structures in people with disabilities and their marginalisation.

The difference between the social and the medical model lies in the causal logic of disability. According to the social model, its cause lies in the social structure. Thus, the basic idea of a social model is that disability should not be considered an individual problem, but life as it relates to a society that imposes responsibility for the shortcomings of human bodily

constraints into the inability of society to anticipate and change to diversity (Bampi et al., 2010).

Bampi et al. (2010) suggest that the main focus of analysis is a way the social model rejects consideration of functional, physiological and cognitive abilities deficits that a person may have, but looks at the ability of society to systematically suppress and discrimination against people with disabilities and negative social sentiment towards disabilities in everyday life. Therefore, disability is located in the broader external environment, and cannot be explained as a consequence of a physical and / or cognitive disadvantages of the individual. So, focusing on the way in which the disability is made socially, the social model prefers the importance of politics, empowerment, citizenship and choice.

The Social Model of Disability (SMD), as proposed by Bailey et al. (2015), argues that people who are disabled are often treated as being different and are thus marginalised by society. This occurs because of a lack of knowledge about disability in general and specific disabilities in particular. According to Lipson and Rogers (2000), society is not sensitive to people who are disabled. They further suggest that being part of a racial or ethnic minority group is more welcomed by society than being disabled. The SMD is therefore based on the notion that equality for disabled individuals is of the utmost importance for a successful society (Disability Junction, 2011). Due to their pale, white skin people with albinism stand out in society as being different especially in those societies that are predominantly black. Their skin colour is accompanied by certain beliefs, negative attitudes and discrimination that sees people with albinism marginalised socially, academically and therefore occupationally (Salewi 2011; Baker et al., 2010)

The SMD has concentrated on two aspects: 1) the fact that the medical model did not identify or explain the socio-political phenomenon of disability and 2) oppression to persons with disabilities who suffer from loss of skills caused by their physical deficit (Anastasiou & Kauffman, 2013). According to other experts, disability is a sociological phenomenon and not a deficit of biological expression (in other words a loss of physical or cognitive function). The meaning of individual defeat in disability is a strictly social. In this context, the explanation for the low level of education or unemployment of the disabled should not be sought in the constraints caused by the individual (or their defeat), but in the social barriers that limit the expression of their abilities (Samaha. 2007).

The removal of disability from the sphere of nature and its transfer to society was a revolutionary theoretical change. As a result of 'seeing' disability as a sociological phenomenon that is not determined by nature, the nature of any conflicts involved in this approach should not focus on therapies but on the politics (in that context and/or country). The first theorists of the SMD were against all individualised explanations of disability. Invalidity should not be understood as an individual problem, a personal trajectory but rather as a consequence of social mechanisms that are unlikely to be sensitive to diversity (Anastasiou, & Kauffman, 2013).

This is supported by Albert (2004) who argued that biological impairments are not the real disadvantage that disabled people suffer, rather they are disadvantaged by the social, cultural, economic and environmental barriers they have to overcome. This suggests that the actual disability is the barrier and causes the social exclusion the disabled are subjected to. Sullivan (2011) used the SMD as a framework to suggest that people who are disabled in anyway should not be classified as being different in society but must be valued in order to fully participate in any social context. Studies indicate that people with albinism are able to perform successfully when environmental conditions are suited for their educational and social needs (Lund & Lynch, 2013; Mashau, 2012)

The SMD however, is critiqued for its lack of a broad definition of disability nonetheless, according to Samaha (2007), the SMD contains an acceptable definition of 'disability.' Nonetheless, a certain disadvantage occurs regardless of the social context as there will always be a group of people whom the model will not characterise (or describe) but who still have a specific cognitive or physical problem. Secondly there is no specific definition as what is a disadvantage and to what extent a deficit can be described as a disadvantage. Proponents of the SMD are also unclear about what the concept of disadvantages or disability issues are (Bampi et al., 2010). As soon social barriers to the reintegration of people with physical disabilities are removed, the invalidity or discrimination is eliminated. Requirements for changes in society, changes in the environment, changes in environmental control systems, changes in social roles and changes in the attitude of people to the community as whole are required for this (Bampi et al., 2010; Samaha, 2007).

The aforementioned paragraphs thus denoted why SMD was deemed appropriate for use in this research as there is recent literature that uses the model to underpin research on various disabilities (Bailey et al., 2015; Sullivan, 2011).

3.3 Summary

This chapter gave an overview of the theoretical underpinnings of the research. The following chapter provides an holistic overview of the research methodology for the investigation.

CHAPTER 4: RESEARCH METHODOLOGY

4.1 Introduction

In this chapter the way the research was undertaken is properly explained which includes the research design, sampling, data collection, data analysis and ethical procedures.

4.2 Research design

For the purpose of this study, the researcher used a qualitative approach approach using an exploratory research design.

4.3 Sampling

4.3.1 Sampling method

According to Latham (2007), sampling involves selection of participants from any given population. The researcher applied purposive sampling to select students with albinism registered at the University of Limpopo. It is a purposive sample because the researcher purposefully selected students with albinism in order to address the research problem. According Etikan, Musa and Alkassim (2015), purposive sampling is a sampling process in which the researcher deliberately chooses specific individuals because of their unique attributes.

4.3.2 Sample size

The available data from the Reakgona Disability Centre (DSU, 2017) indicated that the number of students with albinism registered at the University of Limpopo was approximately 33 students. An appropriate number of participants for the study was discussed with the researcher's supervisor. It was considered appropriate to use 18 students (6 students per focus group = 3 groups). The sample consisted of 50% female and 50% male participants (9 females and 9 males) to ensure gender representivity.

4.4 Data collection

The researcher used a semi-structured interview guide (Appendix 1) in the context of gathering data through focus groups for this qualitative study. The researcher asked questions and probed further when necessary. Focus groups provide the advantage of generating high quality data that is useful in understanding people and their social experiences and challenges (Dilshad & Latif, 2013). According to Harrell and Bradley (2009), a semi-structured interview protocol aims to focus the interview for the purpose of obtaining information relating to a particular subject (either from individual interviews or focus groups).

Data was collected using three focus groups. Each focus group consisted of 6 students (3 females and 3 males in each group). The researcher gathered information using an audio device supplemented with field notes (so that body language can be recorded). Audio recordings were used only with the participants' consent. The interviews took place in the boardroom of the Disabled Students Unit (DSU) to ensure that participants felt comfortable in a familiar environment. Interviews were conducted in English, the medium of instruction at the University, as some participants did not speak the local vernacular.

According to Denzin and Lincoln (2011), focus groups were first used as research method in market research, originated from the 1940s in the work of Russia Bureau of Applied Social Research at Columbia University (United States of America). Focus groups give an idea of how people think and provide everything deeper understanding of the phenomena under study. Focus group is group interviews that give the researcher the opportunity to capture more in-depth information and is more cost-effective than individual interviews (Nagle & Williams, 2013).

The length of the interview varies depending on the topic, the researcher and participants. However, on average, interviews in health care they last between 20-60 minutes (Centre for Disease Control and Prevention [CDC], 2008). Focus groups are usually recorded and observations are made by the research so that no communication form is left out (body language is an important part of all human communication). At the beginning of the focus group, the facilitator must tell participants about the presence of audio recording equipment and assure group members about the confidentiality of the proceedings (informed consent is always obtained).

According to Nagle and Williams (2013), the focus group is an organised discussion on a specific topic for research (or sometimes therapeutic) purposes. This is a discussion guided and controlled by the researcher/facilitator (Ryan, Gandha, Culbertson, & Carlson 2014).

Focus groups offer a particularly productive method for using in qualitative research. The optimal size for focus group is from six to eight participants (with the exception of researchers), but the focus groups can work successfully with no more than three and as many as 14 participants. Focus group interviews allow a relatively homogeneous group to think about it questions asked by the interviewer in a thoughtful way.

The focus group is very important and should, ideally be conducted in an accessible, comfortable, private, quiet and free from distraction venue (Ryan, Gandha, Culbertson, & Carlson, 2014).

Participants were informed that if they experienced distress during the focus group sessions they could be referred to an onsite counsellor who had agreed to take part in the process. In this research no participants reported any type of distress.

4.5 Data analysis

The researcher used Thematic Content Analysis (TCA) to analyse data collected in the proposed investigation. This process develops themes out of the data. Vaismoradi, Jones, Turunen and Snelgrove (2016) state that TCA involves coding by classifying words and phrased into sub-themes and themes and analysing all data collected, through a comparison of these clustered codes.

In addition, Braun and Clarke (2013) assert that TCA in qualitative research is a method that is used for identifying and analysing data. The six phases of analysis presented by Braun and Clarke (2006) were used in this study. Firstly, the researcher familiarised himself with the data. He read and re-read the transcripts intensively and made notes of any observations that were recorded in the field notes. Secondly he coded the transcripts, this involved identifying the important features of the data that were relevant to the research problem. Thirdly, he searched for themes, this involved looking for a common attribute or concept from a group of codes. Themes were generated after identifying the codes found in the data. The fourth step was reviewing a theme which involved checking the relevance of the theme in terms of the study aim and objectives. The fifth step involved defining and naming themes. In this phase the researcher conducted a full analysis of the themes and sub-themes and ensured that each theme told a story. Lastly, the research presented the analysis in this case in the form of a mini- dissertation in Clinical Psychology.

4.6 Quality criteria

According to Anney (2014), based on the methodologies as well as research assumptions, research studies employ different criteria for evaluating reliability and validity. The present study adopted widely accepted qualitative research constructs relating to trustworthiness.

Credibility - Firstly, the findings of this study must be consistent with lived reality which increased their validity. Secondly, according to Shenton (2004), it is important for a researcher to use approaches of questioning and different kinds of data collection methods that have been used, and accepted, by academic peers in similar studies. The methods used for the purpose of this study are congruent with the established methods of qualitative research. Thirdly, the researcher ensured honesty in responses from participants by explaining why they need to be truthful (Anney, 2014; Shenton, 2004). Lastly, frequent debriefing sessions were held with the researcher's supervisor that alerted him to any biases he had. Fundamentally, the supervisor scrutinised all work that was completed and discussed it with the researcher (Anney, 2014; Shenton, 2004).

Transferability - any findings obtained from the study must be able to be applied to similar situations similar before and beyond the present study (du Plooy-Calliers, Davis, & Bezuidenhout, 2014). Shenton (2004) supports this by stating that readers must be able to relate to a particular study and must be able to associate the findings beyond the situation described in that study. This means that the researcher must describe the study in detail and present an accurate literature review so that readers can refer to other studies (thus gain an understanding of the present study).

Dependability - the contents of this study and the methods undertaken are explained properly in this chapter. The findings were also verified by participants after feedback sessions to ensure that their meanings were properly captured (Anney, 2014). This will ensure that researchers, who engage in similar investigations are able to replicate the work and should find some similarities (Shenton, 2004).

Confirmability – according to Shenton (2004), confirmability means that the researcher must be careful to maintain objectivity in their work. The researcher took the necessary precautions in order to report findings consistent with the participants' accounts instead of the researcher's desires. He also engaged in 'bracketing,' which entailed putting his own world view and judgements aside. He did this by engaging in reflexivity (continually reflecting on the research process) and through meetings with his supervisor.

4.7 Ethical considerations

4.7.1 Permission to conduct the study

Permission to conduct was requested through all the appropriate committees at the University of Limpopo. The ethical considerations used in this study were adapted from Terre Blanche, Durrheim and Painter (2009). The Turfloop Research and Ethics Committee form (TREC) from the University of Limpopo was used (See Appendix 2).

4.7.2 Informed consent

The participants were not coerced into participating in the study. This means that the researcher took responsibility for providing information to each participant before the study started. This included informing the participants of the aims and objectives of the research. The participants also had to fill in an informed consent form. If participants had difficulty reading the form they were able to access an audio copy and give verbal consent or use optical devices (provided by the DSU, University of Limpopo).

4.7.3 Confidentiality and anonymity

The researcher did not require participants' personal information as this may have compromised their anonymity. They gave their names (which were not used outside of the study) if they felt comfortable with that. They could also use pseudonyms if they so desired however, after taking part in the focus group sessions these were transcribed into Participant 1, Participant 2, and so on. Participants were also informed that their confidentiality would be maintained however, limitations to this were discussed. For instance, the researcher's supervisor or a counsellor at the University could have been informed of a participants name if he or she became distressed and needed de-briefing (however, this would also have been confidential). In this study no participants reported undue distress and did not ask for (or want) follow up counselling. Participants were thus only required to provide demographic information such as their gender, age and home language.

4.7.4 Deception

The researcher did not deceive the participants in terms of the research or report findings in a biased manner. No deception occurred during this research.

4.8 Summary

The research design and procedures were presented in this chapter. The following chapter gives the research results.

CHAPTER 5: PRESENTATION OF RESULTS AND DISCUSSION

5.1 Introduction

This chapter presents the analysis and the discussion of the findings based on the responses of the participants (students with albinism registered at the University of Limpopo) in the three focus groups conducted. The following themes were found through a reading of the data: a) Students' understanding of albinism, b) Social experiences of students with albinism, c) Academic experiences of students with albinism d) Social challenges experienced by students with albinism in the University of Limpopo, e) Academic challenges experienced by students with albinism at the University of Limpopo, f) Environmental changes necessary for improved social and academic experiences, and g) Psychological impact of the experience of students with albinism. The themes have been conveniently written in table format together with their respective subthemes for ease of understanding.

5.2 Demographical information

The sample for the study consisted of a total of 18 participants. The sample was gender balanced that is, it included 50% females and 50% males. Three focus groups were conducted and each focus group consisted of 6 participants, which included three females and three males. The table provided (table 1) provides a breakdown of demographic information and also indicates which focus group (1,2 or 3) each participant was in.

Table 1: Demographical information of focus groups participants

Participant and Focus Group (FG) (P)	Gender	Age	Ethnicity	Programme of study	Level of study
Participant 1 – FG =1	Male	19	Tsonga	BA	1 st year
Participant 2 FG = 1	Male	23	Venda	Human Resources	Honours
Participant 3 FG =1	Female	20	African	BA Languages	1 st year
Participant 4 FG=1	Female	19	Pedi	B Admin	1 st year
Participant 5 FG =1	Female	19	Pedi	B Admin	1 st year

Participant 6 FG =1	Male	20	Tswana	BA	2 nd year
Participant 7 FG =2	Female	23	Swati	B Admin	Honours
Participant 8 FG =2	Male	23	Pedi	BA	3 rd year
Participant 9 FG =2	Male	20	Pedi	BA	1 st year
Participant 10 FG =2	Male	21	Tsonga	LLB	2 ND year
Participant 11 FG =2	Female	20	Tsonga	Education (Economics)	1 st year
Participant 12 FG =2	Male	24	Swati	Education (Mathematics)	1 st year
Participant 13 FG =3	Male	18	Pedi	BA (Communications)	1 st year
Participant 14 FG =3	Female	18	Pedi	B Psychology	1 st year
Participant 15 FG =3	Male	21	Pedi	BA in Political studies	1 st year
Participant 16 FG =3	Female	20	Pedi	BA (Translation and linguistics stream)	1 st year
Participant 17 FG =3	Female	20	Pedi	Education (Economics)	1 st year
Participant 18 FG =3	Female	18	Pedi	BA in Media studies	1 st year

As indicated in table 1, all the participants indicated that they identify themselves as Africans and not in terms of their disability (that is as albinos).

Table 2: Percentage of participants in each study level represented.

Level of study	1 st level	2 nd level	3 rd level	Honours (Post graduate)
Percentage of students (%)	72.2	11.1	5.6	11.1

The majority of the participants (72.2%) were first entry (level) students at the time the research took place. Two participants (11.1 %) were studying at their second level, one participant (5.6%) was studying at the third level and two of the participants (11.2%) were in a post-graduate level of study (Honours).

Table 3: Emergent themes

	Theme	Sub-theme
5.3	Participants understanding of albinism	5.3.1 Definitions and description of the condition
		5.3.2 Use of sunscreens and Protective clothing
		5.3.3 Use of spectacles and sunglasses
5.4	Social experiences of students with albinism	5.4.1 Myths and misconceptions about albinism
		5.4.2 Overprotective parents
5.5	Academic experiences of students with albinism	5.5.1 Impaired vision associated with albinism.
5.6	Social challenges experienced by students with albinism in the University of Limpopo	5.6.1 Use of derogatory names towards students with albinism
		5.6.2 Inappropriate looks and/or staring
		5.6.3 Negative attitudes from peers
5.7	Academic challenges experienced by students with albinism at the University of Limpopo	5.7.1 Indifferent attitudes from lecturers
		5.7.2 Impaired vision associated with albinism
5.8	Environmental changes necessary for improved social and academic experiences	5.8.1 Adequate awareness on the campus
		5.8.2 Appropriate and adequate assisting devices
		5.8.3 Brightly painted stairs and improved lighting
5.9	Psychological impact of the experience of students with albinism	5.9.1 Psychological stress
		5.9.2 Depression

5.3 Students understanding of albinism

The participants understanding of albinism was explored in the discussions that occurred in the three focus groups. This included how students define their condition. In this discussion they also told the facilitator what they needed on a daily basis in order to make their lives bearable. The following subthemes emerged: a) Definitions and description of the condition, b) Use of Sunscreens and protective clothing and c) Spectacles (reading) and sunglasses.

5.3.1 Sub-theme: Definitions and understanding of the condition

The responses of the participants indicate that their general understanding of albinism is the lack of pigment melanin which commonly affects the eyes and the hair. Others also acknowledged that the lack of pigment leaves them vulnerable to being burned by the sun as well as problems related to their eyesight.

It is lack of pigment melanin in the skin and the eyes (Participant 1: FG =1: Male, 19 years old).

They say it is a lack of pigment melanin in the skin and eyes and the hair. It makes the skin pale, and the eyes become short sighted and the hair produces white and gold. (Participant 2: FG =1: Male: 23 years old)

I don't have melanin, but that question is for those doing science (Participant 9: FG =2: Male: 20 years old).

I'd say it's caused by a mutation of genes, where the gene responsible for generating melanin is either absent or there's a disorder somewhere there. Ya, that's what I can say because that's where it starts (Participant 7: FG =2: Female, 23 years old).

I'd say albinism is a condition where the person lacks the pigment of melanin (Participant 10: FG =2: Male: 21 years old).

I'd also say that it's a condition where by there's little or no melanin and that results in the skin being light and susceptible to sunlight, you can burn easily and your eyes, they are very, very, very short sighted (Participant 8: FG =2: Male: 23 years old).

It is when the skin is pale and normally it becomes easily burned by the sun (Participant 13: FG =3: Male: 18 years old).

I think it is a condition of the skin of which the skin lacks melanin which is responsible for the colour of the skin [melanin] protects the skin from being burned by the sun you see (Participant 16: FG =3: Female: 20 years old).

It is a condition whereby a person lacks melanin and the skin becomes very sensitive to the sun (Participant 17: FG =3: Female: 20 years old).

A skin condition that is not only limited to the skin but to the eyes as well most of us can't walk in the sun without a hat or clothes that cover the skin (Participant 18: FG =3: Female: 18 years old).

The above responses indicate that students with albinism commonly understand and define their condition as the lack of the melanin pigment in the eyes, the hair and the skin which is correct (Manga et al., 2013; Thuku, 2011). They also have a general understanding of the common problems associated with the condition (for instance, impaired vision) and how a lack of melanin in the skin makes them susceptible to sunburn. However, none of the participants stated that they were more vulnerable to skin problems such as cancer. According to Msomi (2014), learners with albinism living in extremely hot regions in South Africa are at a greater risk of sunburn which also renders them more vulnerable to melanoma (skin cancer). Participants are students at the University of Limpopo which is situated in one of the hotter regions in South Africa. It is thus quite worrying that participants did not mention this as it might mean they do not have this knowledge. Additionally, it may be that as there are many social barriers because of their disability, in terms of SMD (Samaha, 2007), they may not go to workshops and other interventions on the campus (because of not wanting to socialise as a result of bullying).

5.3.2 Use of sunscreens and protective clothing

Participants reported that due to susceptibility to being burned easily by the harsh conditions of the sun, they need to use sunscreen in order to protect their skin. Some of the participants also indicated that in addition to sunscreen they also need a specialised lip-balm to protect the sensitive skin on their lips. Participants also reported needing protective clothing as in long sleeved tee-shirts and ordinary shirts made out of thin, sun-resistant material which is expensive.

For me I need my hat because my skin is very sensitive, 10 minutes in the sun and it becomes very red. My sunscreen and my sunglasses are totally necessary **(Participant 3: FG =1: Female: 20 years old).**

Sunscreen is very important, our skin is not the same, some get burnt by the sun fast, some later, for me the sun burns late because when I was young [and] growing up they had been using these things on me from the start, things like aqua [cream]. To protect ourselves from the sun, we need umbrellas, hats. Yes, and then for us they had been giving us sunscreen for free and we didn't get burned **(Participant 5: FG =1: Female: 19 years old).**

“And lip sun, it is a balm for our lips, it is very expensive at clicks and it treats us well and it is very small” **(Participant 3: FG =1: Female: 20 years old)**

“And I think I need to wear long sleeve clothes but that's not my style, you can't be always wearing long sleeve clothes and sunscreen” **(Participant 11: FG =2: Female: 20 years old)**

“Sunscreen. We need sunscreen but it's very expensive” **(Participant 12: FG =2: Male: 24 years old)**

“I need sunscreen that's the one thing we use every day to protect our skin from the sun because our skin can burn easily” **(Participant 14: FG =3: Female: 18 years old).**

Based on the themes discussed above, it would seem that participants unanimously recognise the need to use sunscreens for their skin and the lips in order to protect themselves from vulnerability to the harsh conditions of the sun. Also, participants indicate that as part of this protection from the sun, they have to wear protective clothes such as long sleeve shirts, hats etc. NOAH (2014) indicates that sunscreens are very important in terms of avoiding damage to the skin by the sun. It is also noted that people with albinism cannot move about if they are not wearing protective clothing and sunscreens. A lack of, or inadequate access to sunscreens, can negatively influence their social experiences and even academic excellence in regions such as Limpopo Province. These are societal and environmental barriers that the SMD propose as imperfect experiences in society that can be challenging to those with disabilities (Bailey et al., 2015).

5.3.3 Spectacles and sunglasses

Participants also indicated that they have to wear spectacles in order to assist them with their short sighted vision. They also indicated that they also need sunglasses primarily to dim and protect their eyes from the sun and to limit their access to light as bright light leads to poor vision for people with albinism.

“Ya, I think another thing is with the spectacles they make here at school, they want to zoom things, and with our condition the problem is not that we can’t see far, for that one they cannot change, for us we need dim, we don’t need zoom because we don’t need too much light” (Participant 2: FG =1: Male: 23 years old).

“And the spectacles are for seeing well when you are near” (Participant 5: FG =1: Female: 19 years old).

“Sunglasses are important because if we are lacking pigment, the lack of pigment simply means that we have too much access to light. Our eyes can easily access too much light” (Participant 1: FG =1: Male: 19 years old).

“An umbrella, with a dim colour and not a bright colour because the sun will damage my eyes obviously, I need spectacles for reading and I need sunglasses to avoid the sun” (Participant 7: FG =2: Female: 23 years old).

“We have to wear like spectacles because we are short sighted you see. Sometimes we have to wear like sunglasses for our eyes” (Participant 14: FG =3: Female: 18 years old).

From the extracts of this theme, it may be necessary for people with albinism to have spectacles that will assist in correcting their inherently impaired vision. Also, it seems that people with albinism may need to wear sunglasses with a dim colour in order to decrease the amount of sunlight that their eyes may be exposed to. Special sunglasses (with reading lenses) are also essential for reading and attenuating the sun damage to the eyes (Dart et al., 2010). These authors also state (2010) that these sunglasses like sunscreens are expensive and that some people with albinism may not be able to afford them. This is related to the economic barriers that exacerbate the impairment of some albinos thus their innate abilities according to the SMD (Bailey et al., 2015). If students cannot afford these sunglasses, movement around the University campus will be limited. Their academic progress can also be impeded as they need these tinted glasses in order to read their work in lectures.

5.4 Social experiences of students with albinism

Participants discussed their social experiences as students with albinism verbatim. The responses were predominantly from the first and the second focus groups. Based on the responses given by the participants, the following subthemes emerged from their discussions in all three focus groups: a) Myths and misconceptions about albinism, b) Overprotective parents.

5.4.1 Myths and misconceptions about albinism

The participant indicated that the different myths that people hold about them and their condition impacted their social experiences. The responses also showed that different myths, misconceptions and beliefs about albinism were not only a painful experience in their respective communities but also impacted their social experiences at the University of Limpopo.

“And the myths yooo, just yesterday someone asked me is it true that people with albinism don’t die? I was like eh it is not true and he wasn’t the first one and there’s sayings that people with albinism are this and that” **(Participant 4: FG =1: Female: 19 years old)**

“Some say that we are medicine, some say that when you talk to people with albinism you will have good luck” **(Participant 5: FG =1: Female: 19 years old)**

“...and some would spit out because they were told when you see a person with the condition you must do certain things so that later on in life you don’t have children with the same condition so for me it was not that pleasant until I went to boarding school with people who were like me” **(Participant 8: FG =2: Male: 20 years old).**

Based on the above themes, it can be construed that people in society hold certain beliefs, misconceptions and myths about people with albinism. This is a social experience that negatively affects the quality of life for students with albinism. The myths, misconceptions and beliefs are also accompanied by behaviours such as spitting whenever one encounters a person with the condition which has been described as an unpleasant experience. According to Thuku (2011), due to the myths that surround albinism, albino persons are misunderstood. Myths and misconceptions about albinism leads to negative attitudes from their peers and their communities (Salewi, 2011). Misunderstanding means that albinos are usually marginalised and treated differently from those with normal pigmentation which limits their

integration socially and academically. In terms of the SMD, these are the dynamics which limit people with disabilities (Bampi et al., 2010).

5.4.2 Overprotective parents

The participants are of the view that most parents can be overprotective of them which leads them to having a decreased sense of autonomy and personal choice when it comes to their social experiences. Participants also stated that overprotection from parents may limit their capability to explore the world around them.

“I don’t know but there was this time they wanted to send us for an errand around 6 in winter and I was left behind because I’m albino and it’s late and it for me it did not treat me well because I like to be free” (Participant 4: FG =1: Female: 19 years old).

“True. My parents don’t allow me to go to school alone” (Participant 5: FG =1: Female: 19 years old)

“Me sometimes they protect me, they don’t allow me to go around with people they know or trust” (Participant 6: FG =1: Male: 20 years old)

“For me I still use the same sunlight green bar my mom won’t allow me to use another brand. This is because when I was young my skin would be reactive to other bar soaps so she still sticks on that. She checks if I’m still using the right lotion and if I still have sunscreen and keep me from going outside when it’s hot. They don’t send me anywhere when it’s hot and now they won’t allow me. Growing up they expected me to wear long sleeve at all times but I would cut them and we would fight because of that” (Participant 7: FG =2: Female: 23 years old).

“When we grow up our parents are overprotective of us so it seems like they are limiting our space to explore and know things in the world” (Participant 17: FG =3: Female: 20 years old).

According to the responses of the participants, parents can be overprotective when it comes to children with albinism. Most of the participants indicated that this limits their ability to explore. Notwithstanding the above assertions by most students with albinism, some appreciated and understood the appropriateness of protective parents in view of the dangers and vulnerabilities that surround people living with albinism.

“Even me, even though I’m this old, it’s true. But at the end of the day I understand that it comes from a good place and they just care about us so I understand” (Participant 5: FG =1: Female: 19 years old).

“I think their fear it’s reasonable” (Participant 3: FG =1: Female: 20 years old).

“Though at home they overdoing it but I understand” (Participant 5: FG =1: Female: 19 years old).

“For me also parents are also very protective, like they always forced me to wear long sleeve shirts and when it’s very hot I was forced to call my friends to come over so we can play in the house” (Participant 9: FG =2: Male: 20 years old).

Parents are overprotective of their children living with the condition of albinism. However, overprotectiveness is viewed by people with albinism as hindering their ability to be able to explore their environment. Nonetheless, overprotectiveness can be appreciated as a way of parents trying to protect their children from the environmental challenges that they face. Because of myths surrounding the condition, parents of people with albinism are reluctant to allow their children to freely explore their social environment and let their children to go to school (Msomi, 2014). In terms of the SMD, social constraints such as myths, results in people with disabilities not integrating well into society (Bampi et al., 2010).

5.5 Academic experiences of students with albinism

The participants were able to discuss on their academic experiences that they have experienced as students with albinism. From this theme, there emerged one subthemes namely a) Short sightedness associated with albinism. The theme was discussed as follows:

5.5.1 Impaired vision associated with albinism.

Participants indicated that short sighted eyesight has been a significant cause of most academic challenges they faced growing up. Some of the participant also added that challenges were experienced when they were enrolled in mainstream education.

“Yes, albinism it accommodates with partial blindness so you can agree with that people who attended public schools they could not see very far like, so the chalkboard, the distance between me and the chalkboard” (Participant 1: FG =1: Male: 19 years old).

“For me it was a bit challenging because I started to attend mainstream school before I went to boarding school and it was difficult for me to even focus in class because I didn’t know that I was different from other people and I sit at the back of the class because I felt that I could see because if other people could see why wouldn’t I see because no one ever explained to me that I’m short sighted and on the streets it was very difficult...” (Participant 8: FG =2: Male: 23 years old)

“With me I did my preschool at mainstream so the challenge was that I could not see at the board that’s the challenge I can say stood out but my performance at least was good because at least the teacher understood, so during break time she would ask that I remain so that I can check if I did everything” (Participant 7: FG =2: Female: 23 years old)

“I attended both special and mainstream and at mainstream school it was difficult, sometimes I could not see at the board even when I’m in front” (Participant 13: FG =3: Male: 18 years old)

“Another thing is that while I was still at mainstream school, the challenge for me I didn’t feel like I was part of the people there I had friends but some did not understand me and it was difficult for me to socialise. But then when I went to special school there was a lot of albinos and I felt like part of family” (Participant 18: FG =3: Female: 18 years old).

Impaired vision is closely linked to the condition of albinism. Impaired vision, especially in mainstream schools, affects academic performance as students are unable to see properly on the board. This academic challenge can be perpetuated by teachers who do not comprehend the challenges that are faced by students with albinism. Ndomondo (2015) also indicates that students with albinism are likely to take longer finishing academic work which can negatively affect their academic performance, as compared to other students. Environmental barriers also disadvantage students with albinism (Albert, 2004; Sullivan, 2011). For instance, stairs and dark corridors that are difficult to navigate. Furthermore, in terms of SMD this can have an impact on their social experiences as they cannot fully integrate with some of their peers who may not understand their challenges.

5.6 Social challenges experienced by students with albinism in the University of Limpopo

Students have different social experiences in comparison with other students registered at the University of Limpopo. Participants were able to respond to questions regarding their social challenges in the university. The following are the subthemes that emerged from the contributions of participants in the focus groups discussions: a) Name calling, b) Inappropriate looks and/or staring and c) Discrimination

5.6.1 Use of derogatory names towards students with albinism

Most of the participants highlighted that name calling is a serious social challenge that they experience in the university. The participants indicated that name calling was very hurtful and generally made them uncomfortable.

“I have a problem with people calling me by names such as ‘mlungu’ or makhwetla”
(Participant 6: FG =1: Male: 20 years old)

“The other problem is that they call us with other names” **(Participant 11: FG =2: Female: 20 years old)**

“It was not nice at all, people would call me names and it hurt and it made me feel uncomfortable” **(Participant 15: FG =3: Male: 21 years old)**

“For me it wasn’t okay because although my family made me feel comfortable but the community would call me names like mukhuwa” **(Participant 18: FG =3: Female: 18 years old).**

Some participants also indicated that although they can often cope with being called derogatory names by someone that they are closely bonded to (as they explained it is usually in a gentle teasing and humorous way). However, they find the use of derogatory names insulting when they are called names by strangers. They indicated that persons close to them may be showing affection whilst a stranger may do so due to a lack of understanding of the condition.

“I also do socialise with people who don’t have albinism and sometimes we do joke about my condition, so to them they don’t take it too seriously like we feel sorry for her, as soon as I see that I walk away but with the friends I have now it’s not something that hurts me they even joke about my skin colour like ‘mlungu wa rena’,

'legowa' and last night they were laughing at me because of mosquitos, I cannot see mosquitos so they would be like my friend they will just finish you because you cannot see mosquitos so for me they joke about my condition" **(Participant 7: FG =2: Female: 23 years old).**

"I think it all depends on the kind of relationship you have with that person if you are not in good terms with that person and they come and say those things, you can just send them to all" **(Participant 9: FG =2: Male: 20 years old).**

"I love 'legowa'" **(Participant 5: FG =1: Female: 19 years old)**

Students with albinism indicated that they do not welcome being called by derogatory names that are based on a lack of understanding and misconceptions about the condition. As indicated by the above extracts, being called by derogatory names is a problem associated with their social experiences. Participants also indicated that while they take offence being called by derogatory names, they do welcome the gesture from those they are close to than persons they are not personally acquainted with. According to Thuku (2011), derogatory names are one of the sources of negativity from society which leads to stereotyping and discrimination. Lund and Lynch (2013) also state that derogatory name calling can lead to problems such as bullying in schools. Discrimination, stereotypes and bullying negatively affect the social experiences of students with albinism. This may lead them to become depressed and in turn, struggle academically. The SMD suggests that when people with disabilities encounter negative attitudes and name calling their social interaction is limited; which can lead to lack of self-confidence (Bailey et al., 2015).

5.6.2 Inappropriate looks and/or staring

Participants indicated that being inappropriately looked or stared at is an uncomfortable social experience in the university campus. Majority of the students mentioned that inappropriate looks (staring) made feel like there is something very wrong with them.

"Even in class when we arrive late oh my God! The attention" **(Participant 3: FG =1: Female: 20 years old)**

"Ya it happened sometime you'd ask someone where can you find this, where can I find this shop? You'd greet people and they would not reply and you get unpleasant looks from people. It wasn't easy because you'd be reminded that I'm not the same as everyone..." **(Participant 7: FG =2: Female: 23 years old)**

“ya to add on that one of unpleasant looks, some people can make you feel like there’s something wrong with you. Whenever you are passing people will be looking at you like there’s something wrong. That one I experienced in some places and not from my place” (Participant 10: FG =2: Male: 21 years old)

“there’s also the issue of negative talk like maybe you arrive at a place and you can see the looks that we take ourselves as being better because we can’t socialise with them so you going to be on the other side and when it comes to other people they look at you in a different way, they have certain comments” (Participant 13: FG =3: Male: 18 years old)

“Sometimes when you are walking or at the cafeteria you see some of the looks you get I don’t know if they are just interested in me or they are shocked to see an albino” (Participant 17: FG =3: Female: 20 years old).

The above responses from participants indicate that inappropriate looks, as well as staring, affects how students with albinism perceive themselves. The responses may also suggest that inappropriate looks and staring can negatively affect their self-esteem as well as their confidence in social situations. Phatoli et al. (2015), state that students with albinism experience ‘staring’ very negatively and it is also associated with exclusion by their peers. In terms of the SMD inappropriate looks or staring is very uncomfortable for students with albinism. This impedes their full social integration and leads to negative outcomes in their social experiences (Bailey et al., 2015).

5.6.3 Discrimination

According to the participants, their experiences due to their condition can be associated with being undermined in social situations. Most of the participants indicated that they feel that they have to prove their capability at university level to a greater degree than students without a disability like albinism.

“I remember in my first year we had to get our scripts back and some guy behind me saw my scripts and he said Sisi, is that your script, and I said yes and he said no it can’t be yours, it can’t be. And with group assignments, we’d struggle to get a group and no one wanted to be in our group because they thought we are slow learners. At church as well, I’ve always had to prove myself that I can do it as well, even at home

and at school I always had to prove myself that I'm also capable, I'm good at singing, look at me" (Participant 7: FG =2: Female: 23 years old).

"Almost everywhere in campus, because if they look at you they think you are not capable of doing somethings so it becomes a challenge for me that I have to prove to you that I can do it and somewhere somehow it ends up hurting me or giving you a perception that like albinos don't understand so well and end up doing something in a great measure then someone will say that we don't understand but I was trying to show that person that I can do it" (Participant 2: FG =1: Male: 23 years old)

"To add, okay to add on that it starts with our government because there are certain occupations that occupy people with albinism and they'll say no they are trying to protect us blah blah blah, for example, working in the sun or being exposed to the sun, yes they are protecting us but somewhere somehow they are discriminating us before we can go to what people think or do..." (Participant 1: FG =1: Male: 19 years old)

"For me when I was still in primary, I passed my grade 3 and then they said I should go to princehoff, and at princehoff they said I did not pass well my grade 2 and if I come here they would take me to grade 2 so I won't progress to grade 4 then I went back to mainstream school and I did my grade 4. I failed my grade 4 because I wasn't coping and the teachers at the board did not care and then I went to Bosile and I did my grade 4 there and my performance started to improve and then I passed my grade 4" (Participant 8: FG =2: Male: 23 years old).

Even making friends can be difficult, say in class they say there must be groups then you don't get to choose who you want to be with because I am afraid to approach them because they might reject me. Then I realised that just because I am an albino people think that even intellectually we don't function properly" (Participant 12: FG =2: Male: 24 years old).

"Ya, eish I don't know why but people look at you like you are half human hey, we are just as competent and able to do what normal people can do but most of the time no one believes in us enough to give us a chance" (Participant 13: FG =3: male: 18 years old).

Based on the above extracts from the participants' responses, it can be deduced that students with albinism often feel undermined which compels them to feel like they always have to prove themselves in social situations. Participants indicated that they constantly put more effort into mixing socially in order to validate their capabilities and competencies against their peers. Some extracts indicate that this validation occurs in order for students to feel accepted or recognised among their peers, or in any social situations. According to Bailey et al. (2015), discrimination leads to societal exclusion. Nzelwa (2016) indicates that discrimination, relating to SMD, creates problems for people with albinism as they do not have complete access to education and social events as a result of their negative experiences.

5.7 Academic challenges experienced by students with albinism at the University of Limpopo

Participants were able to contribute to the questions during focus group discussions and they were able to respond on matters concerning their academic challenges they have faced in the University of Limpopo. The following subthemes were extracted from the responses given in the three focus groups: a) Indifferent attitude from lecturers, b) Short sightedness, and c) Small projectors and screens in the lecture halls.

5.7.1 Indifferent attitude from lecturers

Participants unanimously pointed out that most lecturers on campus at the University of Limpopo do not care enough about their needs of students with albinism. The participants reported that most of the lecturers did not care about their ability to see slides in class (most are too small), which impacts their concentration and ability to prepare for tests and exams. They also indicated that lecturers continuously forgot to deliver question papers to Reakgona Disability centre (DSU) where they sit for their tests and exams. Moreover, it was indicated that lecturers are often impatient with students with albinism due to their recurring visits to their offices to remind them of the needs associated with their condition.

"I think it's just those ones we've discussed like when lecturers forget us"
(Participant 5: FG =1: Female: 19 years old).

"Even the lecturers, they should just understand that we cannot see when they come with their slides on the projector I can't see so like they must bring something in class for me like printed slides so that when they are looking at their slides I'm also able to look here because I can't see at the projector and then the minute I can't see

what's on the projector I lose concentration so at least let them make something so I can be able to see and then I am able to follow at the same pace” (Participant 3: FG =1: Female: 20 years old)

“Yes, if I can't see on the projector like it affects that module because from there even the English you are speaking for me I just go to class just for the lecturer to see me I just fail nonetheless” (Participant 3: FG =1: Female: 20 years old).

“Yes, sometimes you find that they didn't make a question paper for you and after that they tell you, even if you want to write, that no come on this day and see me in my office and when you come they tell you that because others have already written that paper we will make a new question paper for you and you find that they are giving you things that are different from what others have written so that's not fair” (Participant 8: FG =2: Female: 23 years old).

“Ya that one is unfair, can you believe I wrote a sick test because there was no question ya large print when other student are writing and I wrote last week, a week before exams so it is unfair” (Participant 9: FG =2: Male: 20 years old).

“For me I can't see on the board and it really hurts because you easily lose concentration, you can't focus when you can't see a thing on the board. The other students are able to focus because they are busy taking notes and when they ask questions they easily answer while looking on the board so I'm forced to listen and do nothing but listen and I can't write as fast as the lecturer is busy speaking. I remember this other time I asked the lecturer, sir can you please slow down because I have to write while listening to you and I can't see on the board and he said I'm sorry, I will. 5 minutes later on went back to the routine and he said that this is how I speak. So I was expected to understand instead of him understanding me because I'm the one with a challenge so for me that's my biggest problem. I find it hard to concentrate in class when I can't see anything” (Participant 7: FG =2: Female: 23 years old).

The participants also indicated that although they experience indifferent attitudes and behaviours from most of their lecturers that there are some (very few) lecturers who show that they care.

“But some of them try. Some” (Participant 4: FG =1: Female: 19 years old).

“Yes, but very few” (Participant 3: FG =1: Female: 20 years old).

“I would say that some do and some don’t, I say some because some take the effort to understand our needs and like for example when we are writing a test they forget to arrange us that we write at DSU, but some you don’t have to constantly remind them to bring question papers at DSU” (Participant 14: FG =3: Female: 18 years old).

“I also think they don’t care most of them but it’s not all of them some make an effort shame” (Participant 15: FG =3: Male: 21 years old)

“They do try; I just think some just need to be more aware that there are students with albinism even in the lecture halls they must try to care more so our lives can be easier like other students” (Participant 18: FG =3: Female: 18 years old).

Lack of understanding of the needs of students with albinism by lecturers at the University of Limpopo helps perpetuate the academic challenges that the students with albinism experience. According to the above extracts from the participants, lecturers are not fully sensitive to the needs of students with albinism as shown by the indifferent attitudes that students receive from lecturers in class and in their offices. Participants did note that this does not apply to all lecturers as few of the academic seem to be sensitive to the different needs of students with albinism. Inadequate support and lack of understanding from educators exacerbates challenges that students with albinism face (Msomi, 2014). The negative attitudes of lecturers with regards to students with albinism limits them from expressing their abilities (Samaha, 2007) as compared to other students which relates to notions suggested by the SMD.

5.7.2 Impaired vision associated with albinism

The participants indicated that because they have impaired vision and are short sighted, they are unable see in class which minimises their ability to concentrate and understand what is being discussed in class. They reported that they also feel discouraged whenever they have to attend class due to the difficulty seeing the whiteboard or material projected onto a whiteboard.

“Even the lecturers, they should just understand that we cannot see anything when they come with their slides on the projector I can’t see so like they must bring something in class for me like printed slides so that when they are looking at their slides I’m also able to look here because I can’t see at the projector and then the

minute I can't see what's on the projector I lose concentration so at least let them make something so I can be able to see and then I am able to follow at the same pace” (Participant 3: FG =1: Female: 20 years old).

F: Do you think it affects your potential to do greater than you are doing?

“Yes, if I can't see on the projector like it affects that module because from there even the English you are speaking for me I just go to class just for the lecturer to see me I just fail nonetheless” (Participant 3: FG =1: Female: 20 years old).

“For me I can't see on the board and it really hurts because you easily lose concentration, you can't focus when you can't see a thing on the board. The other students are able to focus because they are busy taking notes and when they ask questions they easily answer while looking on the board so I'm forced to listen and do nothing but listen and I can't write as fast as the lecturer is busy speaking. I remember this other time I asked the lecturer, sir can you please slow down because I have to write while listening to you and I can't see on the board and he said I'm sorry, I will. 5 minutes later on went back to the routine and he said that this is how I speak. So I was expected to understand instead of him understanding me because I'm the one with a challenge so for me that's my biggest problem. I find it hard to concentrate in class when I can't see anything” (Participant 7: FG =2: Female: 23 years old).

“I always have a problem seeing on the projector because I'm very short sighted so it is hard to understand what the lecturer is teaching so luckily I manage to pass my subjects but I think it becomes a disadvantage compared to other normal students” (Participant 11: FG =2: Female: 20 years old).

“Sometimes it better to not go to class because even when I go there I can't see what the lecturer is talking about on the slides so I see it as being useless sometimes because I cannot concentrate. Some at least post the notes on blackboard but some don't really care about us so it's hard” (Participant 16: FG =3: Female: 20 years old).

Most of the participants also reported that the projectors or screens in most lecture halls are small and they are unable to see what is displayed on them. They also indicated that due to

the inability to see their concentration and understanding of the subject matter becomes compromised and which affects their academic performance.

“Even the lecturers, they should just understand that we cannot see when they come with their slides on the projector I can’t see so like they must bring something in class for me like printed slides so that when they are looking at their slides I’m also able to look here because I can’t see at the projector and then the minute I can’t see what’s on the projector I lose concentration so at least let them make something so I can be able to see and then I am able to follow at the same pace” (Participant 3: FG =1: Female: 20 years old).

F: Do you think it affects your potential to do greater than you are doing?

“Yes, if I can’t see on the projector like it affects that module because from there even the English you are speaking for me I just go to class just for the lecturer to see me I just fail nonetheless” (Participant 3: FG =1: Female: 20 years old).

“I always have a problem seeing on the projector because I’m very short sighted so it is hard to understand what the lecturer is teaching so luckily I manage to pass my subjects but I think it becomes a disadvantage compared to other normal students” (Participant 12: FG =2: Male: 24 years old).

“Sometimes it better to not go to class because even when I go there I can’t see what the lecturer is talking about on the slides so I see it as being useless sometimes because I cannot concentrate. Some at least post the notes on blackboard but some don’t really care about us so it’s hard” (Participant 16: FG =3: Female: 20 years old).

“Yes and maybe do something about some of the projectors so that we can see” (Participant 17: FG =3: Female: 20 years old).

Impaired vision associated with albinism makes it difficult for students with albinism to see displays on small screens and projectors. Based on the above extracts, some students with albinism face academic challenges because of this. Most of the students stated that they tend to lose concentration as they are unable to move at the pace of the lecturer. The participants reported that impaired vision negatively affects their academic performance. Impaired vision affects the ability of students with albinism to be able to read small fonts or see at a distance (Kiishweko, 2017). The inability to read at a distance in class is just one of the challenges

that students with albinism face and is an academic and social disability (as posited by the SMD).

5.8 Environmental dynamics that lead social and academic challenges

The participants were able to share some of the improvements that they thought university management could implement in order to improve their social and academic experiences at the University of Limpopo. The following themes were extracted in this area probed by the researcher: a) adequate awareness in the campus, b) appropriate and adequate assisting devices, and c) brightly painted stairs and improved lighting.

5.8.1 Adequate awareness in the campus

The majority of the participants indicated that in order to improve their social experiences at the University of Limpopo more awareness campaigns are needed. This is in order to educate their peers and the whole university community (all staff) about albinism. They also stated that although there are efforts to try and bring awareness about the condition at the annual disability day, there needs to be specific and regular awareness campaigns about albinism.

“Let there be awareness campaigns so that people can know there are albinos in the campus because they don’t understand so maybe if they can be made aware about our condition. Even though there are some awareness campaigns people don’t attend like they don’t care so for me because people don’t care I just have the attitude that I don’t care what they think about me even if they understand me or not I don’t care I just tell myself that I just came to get my degree and leave” (Participant 3: FG =1: Female: 20 years old).

“I think we must have more workshops educating people about albinism and as DSO we agreed that next year we won’t have an annual disability day, but an annual disability week because we believe that a day is not enough” (Participant 9: FG =2: Male: 20 years old).

“...and as much as the health centre, isn’t they know more about this thing, I believe they know more than we do, as much as they have awareness days for AIDS, STIs, STDs, pregnancy, sex whatever, I think they should consider this as well because they know very well that there are students living with disabilities in this campus, there are students with albinism in this campus so I think even them they need to take this into consideration” (Participant 7: FG =2: Female: 23 years old).

“I think they should put more emphasis in September, because its albinism awareness month because this year nothing much was done” (Participant 8: FG =2: Male: 23 years old).

“Students and lecturers must be educated about our condition and disability so that they can also stop some of the things like names and staring. I think if lecturer knew more about our condition then they would meet us half way by providing slides in class and stuff” (Participant 18: FG =3: Female: 18 years old).

Increased awareness about albinism among students and lecturers at the University of Limpopo can improve the social and academic experiences of students with albinism. Based on the extracts above, it can be construed that a better understanding of the condition as well as the challenges associated with it can lead to more positive attitudes from peers and lecturers. This would facilitate improved integration for students with albinism in the University of Limpopo. The purpose of increased awareness is to increase curiosity about albinism with the hope of reducing myths and unpleasant attitudes (Selepe, 2007). When people have gained awareness they will be able to appreciate students with albinism and social and academic experiences can improve. This will ultimately lead to fewer social and environmental barriers that suppress students with albinism with reference to the SMD (Lund & Lynch, 2013).

5.8.2 Appropriate and adequate assisting devices

Participants reported that the management need to provide appropriate and adequate assisting devices in order to cater for their needs. They reported that some of the devices they are currently provided with are a) not enough to cater for the needs of students with albinism or b) inappropriate in assisting them with their needs. To meet this challenge, participants were of the view that it would be best if the management consulted with them more in order to be aware of their needs.

“I think they should provide assisting devices in time before we fail because they wait for us to complain that we can't do this because of this they don't even do much” (Participant 2: FG =1: Male: 23 years old)

“....and I would like the management to add to the equipment made for us because now it's just 3 or 4 so if there's someone sitting there does that mean I have to go

back? Because I can't see on the small screen” (Participant 7: FG =2: Female: 23 years old).

“On that one I want the management to know that, you see with students who are totally blind? They use a software called Jooste, I want the management to install them in all computer labs because they are isolating us” (Participant 9: FG =2: Male: 20 years old).

“We need better devices for us. Like now they tried like to give us some computers with bigger screens so we can see but if they can work on maybe providing assisting devices at important places in the campus like in the computer labs because even though we are not that many I feel they are not enough. And at least if there were more at the labs we would be able to do like our school work with our classmates in the labs and not be separated” (Participant 17: FG =3: Female: 20 years old).

The above extracts indicate that appropriate and an adequate provision of assistance devices to students with albinism can improve how they integrate academically at the University of Limpopo. Most of the participants are of the view that although the University does provide assistance devices they are not adequate. Most of the participants also indicated that management should consult the students more in this regard. Students with albinism require proper assistive devices which include optical devices and computers for improved learning (Lund & Lynch, 2013; Ndomondo, 2015). According to Albert (2004), people with disability (including students with albinism), have to not only overcome social and cultural, but also economic and environmental barriers Lack of proper assisting devices increases academic challenges and also leads negative social experience as students with albinism become separated from their peers in academic institutions such as a university according to SMD.

5.8.3 Brightly painted stairs and improved lighting

Participants indicated that the management of the University has to look into painting stairs as they are unable to see at certain locations for instance, the stairs at the library. They also indicated that if the steps were painted with a brighter colour they could easily identify them (day and night).

“That side of the library, I can't see those steps. They've been complaining about the matter even I came to the university. So if they could paint those with a bright colour that would be nice” (Participant 4: FG =1: Female: 19 years old).

“The library steps need to be painted seriously not with a dark colour, something like yellow like even in the middle of the day it’s just worse because the light is too bright” (Participant 10: FG =2: Male: 21 years old).

“They need to paint the steps in colours we can see so it’s not difficult for us to go around the campus at night and during the day because the sun affects our eyes” (Participant 12: FG =2: Male: 24 years old).

“...and at night some of the steps are too dark so we they can put lights in those places. It’s not us alone who cannot see those steps even normal students cannot see at night so more lights would help in those places” (Participant 14: FG =3: Female: 18 years old).

In addition to brightly painted stairs (fluorescent paint), based on the responses during focus groups discussions, some of the students with albinism indicated that more lighting, to improve visibility around the campus, is needed.

“There are also some by that side of admin like you have to torch there’s no light there, next to the stuff cafeteria” (Participant 1: FG =1: Male: 19 years old).

“I think we just need more lights like where there are steps” (Participant 6: FG =1: male: 20 years old).

“More lights should be put up to help us see at night especially where we walk through every day like to the lecture halls” (Participant 9: FG =2: Male: 20 years old).

“..and at night some of the steps are too dark so we they can put lights in those places. It’s not us alone who cannot see those steps even normal students cannot see at night so more lights would help in those places” (Participant 14: FG =3: Female: 18 years old).

The above extracts suggest that better lighting around the campus of the University of Limpopo can improve how students with albinism navigate around the campus, especially during the night. Also, participants indicated that the management should paint some of the steps with brighter colours in order to help them navigate better. Kiishweko (2017) reports that the lack of certain services, such as improved lighting at night deters students with albinism from attending classes and going to libraries in the evening. This is due to

difficulties associated with their vision or fear for their safety. The inability to be able to easily go to class or the library can lead to academic challenges and poor academic performance for students with albinism. In terms of the SMD, the definition of a disability is not only limited to societal barriers but also includes environmental barriers (Albert, 2004; Sullivan, 2011).

5.9 Psychological impact of the experience of students with albinism

5.9.1 Psychological stress

Participants indicated that they become stressed due to lack a lack of communication regarding their study notes. The participants also indicated that delays, with regard to access of study materials, disadvantages them in that it gives them little time to prepare for examinations.

“It’s just stress even during exams other students are aware what was happening in class and you just waiting for notes and it gives us pressure” (Participant 5: FG =1: Female: 19 years old).

“Some lecturers don’t post on blackboard and at least other students copied notes in class I have to stress with a textbook and a textbook has too much information you don’t know where to start” (Participant 3: FG =1: Female: 20 years old).

The above extracts indicate that delays in access to study material can be the precipitator of psychological stress for students with albinism. According to the above responses, these delays create pressure for students with albinism due to a lack of guidance in their preparations for their examinations. For disabled students, in this case students with albinism, stress is mainly due to styles of teaching in classes which primarily excludes students with disabilities (Kiishweko, 2017). Psychological stress is likely to cause poor academic performance and generally unpleasant social experiences for students with disabilities in terms of the SMD (Lund & Lynch, 2013).

5.9.2 Depression

Some of the participants indicated that they often experience feeling depressed which is mostly caused by their academic experiences. The participants reported that they no longer care about other people's attitudes and have lost interest in attending their classes.

"I think it affects us psychologically, we become emotionally detached and depressed, like you don't care because people don't care because of their negative attitudes" **(Participant 2: FG =1: Male: 23 years old).**

"I experience depression during tests because I have to study something that I didn't get in class and its stressing" **(Participant 1: FG =1: Male: 19 years old).**

"Sometimes it better to not go to class because even when I go there I can't see what the lecturer is talking about on the slides so I see it as being useless sometimes because I cannot concentrate. Some at least post the notes on blackboard but some don't really care about us so it's depressing" **(Participant 3: FG =1: Female: 19 years old).**

"It can be depressing hey. Ah that's why sometimes I feel like not going to class" **(Participant 15: FG =3: Male: 21 years old).**

Based on the above, it can be deduced that the challenges that students with albinism face lead to feelings of depression. The above extracts also indicate that some students lose interest in attending their classes which disadvantages their academic performance while some may also have feelings of hopelessness due to the negative attitudes they encounter due to their challenges. Challenges such as social exclusion in terms of the social model and consequently poor self-esteem can lead to psychological conditions such as depression and anxiety in terms of the SMD (Phatoli et al., 2015).

5.10 Discussion of findings

The SMD is a model of disability that does not explain disability on the basis of physical impairments but views disability as a result of societal constraints and attitudes such as social, cultural and economic exclusion. These hinder people with disabilities generally (and albinism specifically) from fully participating and integrating into their communities (Bailey et al, 2015). Because they are different from other people, their abilities are not limited so much by their disability but by their being marginalised from society (Samaha, 2007). The discussion below reveals how the participants' experiences are underpinned by SMD:

The findings of this study highlighted the social and academic experiences that are faced by students with albinism registered at the University of Limpopo. It was revealed that the sample defines and understands albinism as a condition that is characterised by a hereditary reduced amount, or lack of melanin, in the skin, eyes and hair. The definition by the sample supports definitions from various other studies on albinism (Baker et al, 2010; Lund & Lynch, 2013; NOAH, 2014).

The sample of students recognised sunscreen as an essential daily need. Sunscreen protects the skin from exposure to ultraviolet radiation as reduced melanin or lack of melanin in people with albinism renders the skin vulnerable to excessive skin cancers. It also eliminates the vulnerability to skin conditions such as skin cancers. The importance of sunscreen in protecting the skin from sun burns and skin cancer in people with albinism was also reported by Matshovhana and Mulibana (2014) and NOAH (2014). Students with albinism also have to wear protective clothing such as spectacles and hats whenever they have exposure to the open sun (NOAH, 2014). However, participants were not aware of the high risk of melanoma (skin cancer) associated with albinism. This is problematic because reduced production of the melanin pigment invites various disability and social challenges that tends to affect experiences that people with albinism have. These includes impaired vision, susceptibility to skin cancer due to the harsh conditions of the sun, discrimination due to beliefs, myths and misconceptions. All of these have a direct impact on the social integration and academic performance of students with albinism.

Findings also indicated that myths and beliefs about people with albinism were what participants perceived as a reason for ‘overprotective parents.’ This relates to parental fear for their safety as found in previous research (Ndomondo, 2015).

The findings of this study also suggest that students with albinism have various social challenges at the University of Limpopo. According to the research participants, they are called by derogatory names which leads to an unpleasant social experience. Ndomodo (2015) and Selepe (2007) have also found that use of derogatory leads to emotional pain in persons with albinism. Although students with albinism may accept the gesture of being called by names such as *legowa* by a close friend, it is perceived as derogatory when used by strangers. The study findings also indicate that inappropriately looking and/or staring at students with albinism is construed as offensive and negatively affect how students with albinism perceive themselves.

Some students with albinism reported discrimination because of their condition and pale white skin. Similar phenomena have been reported in other studies (Mswela 2016; Mswela & Slabbert, 2013). Discriminatory attitudes from peers and society forces students with albinism to feel that they have to prove their capabilities to a greater extent than a person who does not have albinism. Results also suggest that students with albinism are overlooked both socially and academically.

Students with albinism also face academic challenges as a result of their condition which supports previous research (Lund & Lync, 2013). The results indicate that academic challenges are linked to a lack of proper assisting devices and equipment in the lecture halls. It was the view of most of the participants that the majority of lecturing staff do not satisfactorily cater to the needs of students with albinism. In this study although students with albinism complained to lecturers that they could not see slides or notes they were largely ignored (although some staff did help). These results are synonymous to those of studies conducted in pupils in mainstream schools (Lund & Lynch, 2013).

Small screens and lecture notes that are not in a large font perpetuate lack of academic integration for students with albinism. This is also related to visual impairment that is associated with the condition. This is supported by Baker et al. (2010), who report how visual problems in the classroom affect students with albinism negatively at the University of Venda.

Study findings also reveal that students with albinism thought that their social and academic experiences could be improved. Firstly, participants suggested more awareness programmes about albinism, for both staff and students, are needed to increase knowledge (and prevent discrimination). Secondly the study findings indicated that as part of improving social and academic experiences of students with albinism, there need to be increased lighting (especially near stairways) and brightly painted stairs (at the University) so that students with albinism can navigate their way around campus during the day and night.

Social and academic challenges also affect students with albinism psychologically. It was indicated that students with albinism are negatively affected by the way people react to their condition. Furthermore, psychological stress (especially during examinations) can lead to feelings of depression and lack of self-confidence whenever students with albinism face social and academic challenges.

5.11 Strengths and Limitations of the study

5.11.1 Study strengths

The study used a qualitative approach and an exploratory research method which is appropriate when looking at the in-depth experiences of specific groups. This approach has been used in other studies of disability (Maotoana, 2014). Furthermore, the experiences shared by participants were closely related to circumstances in the reported literature (Baker et al, 2010; Dart et al, 2010; Kiishweko, 2017; Msomi, 2014; Phatoli et al 2015; Salewi, 2011).

5.11.2 Study limitations

The study is a qualitative study thus findings cannot be generalised.

5.12 Recommendations arising out of the research

The following recommendations, arising out of the research are made.

- There needs to be more studies on the experiences of students with albinism conducted in a university context as there seems to be little literature concentrating on this area. A broader study using a mixed-methods approach and different university communities should be undertaken.
- The management of the University of Limpopo and various learning institutions need to work together and consult with students with albinism in identifying the needs of students in order to assist students with having better and integrated academic and social experiences.

5.13 Overall conclusion

The experiences of students with albinism are beleaguered with difficulties related to social exclusion and academic challenges. It was revealed that poor vision, discrimination and use of derogatory names are some of the most problematic experiences for them. This can lead students with albinism to becoming vulnerable to psychological conditions such as stress and depression.

Lack of support both environmental (dark steps and corridors), social (discrimination) and academic (lecturing staff not providing academic or emotional support) were revealed as problems for students with albinism registered at the University of Limpopo.

Ultimately, awareness about albinism can equip society and institutions such as the University of Limpopo with the necessary knowledge that will improve sensitivity towards the needs of students with albinism.

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APPENDIX A: SEMI-STRUCTURED AND FOCUS GROUP INTERVIEW QUESTIONS

The questions are semi structured and follow-up questions (or probes) will be asked where necessary to gain clarity. To allow the participant to settle down the research will be explained and demographic questions asked first.

1. How old are you?
2. What is your gender?
3. What is your ethnicity?
4. What programme are you studying?
5. What year of study are you?

Semi-structured interview questionnaire for the focus groups.

1. How would you explain the condition of albinism?
2. How did you feel growing up with the condition?
3. What do you need, in everyday life, in order to minimise problems associated with albinism?
4. Have you ever experienced any social difficulties that you relate to your condition?
5. Have you ever experienced any discrimination because of your albinism?
6. Have you ever experienced any academic difficulties that you relate to albinism?
- g. Do you socialise with peers that do not have albinism at the University?
7. What have your social experiences been like at the University?
8. Do you feel your peers (non- albinos) accept you? If you do (or don't) explain why.
9. Do you feel your lecturers accept you? If you do (or don't) explain why.
10. Do you think that your albinism affects your ability to integrate into your peer group at UL? If yes (or No) explain why.
11. Do you have any social challenges that you would like to discuss?
12. Do you have any academic challenges that you would like to discuss?

13. What improvements do you think the university can implement in order to improve your social experiences?

14. What improvements do you think the university can implement in order to improve your academic experiences at the university?

15. Do you think, your experiences at the University have any impact on you psychologically? If the answer is yes please explain why.

16. My final question is: Do you have anything else that you would like to add?

APPENDIX B: TREC (TURFLOOP RESEARCH ETHICS COMMITTEE) ETHICAL CLEARANCE FORMS

FORM B – PART I

PROJECT TITLE: THE SOCIAL EXPERIENCES AND ACADEMIC CHALLENGES FACED BY STUDENTS WITH ALBINISM AT THE UNIVERSITY OF LIMPOPO

PROJECT LEADER: Mr Dzunisani Innocent Baloyi

DECLARATION

I, the signatory, hereby apply for approval to conduct research described in the attached research proposal and declare that:

1. I am fully aware of the guidelines and regulations for ethical research and that I will abide by these guidelines and regulations as set out in documents (available from the Secretary of the Ethics Committee); and
2. I undertake to provide every person who participates in this research project with the relevant information in Part III. Every participant will be requested to sign Part IV.

Name of Researcher: Mr Dzunisani Innocent Baloyi

Signature: DI Baloyi

Date: 03.10.2017

For Official use by the Ethics Committee:

Approved/Not approved

Remarks:.....
.....
.....
.....

Signature of Chairperson:.....

Date:.....

FORM B – PART 11

**PROJECT TITLE: THE SOCIAL EXPERIENCES AND ACADEMIC CHALLENGES
FACED BY STUDENTS WITH ALBINISM AT THE UNIVERSITY OF LIMPOPO**

PROJECT LEADER: Mr Dzunisani Innocent Baloyi

Protocol for conducting research using human participants

1. Department: Psychology

2. Title of project: **THE SOCIAL EXPERIENCES AND ACADEMIC
CHALLENGES FACED BY STUDENTS WITH ALBINISM AT THE UNIVERSITY
OF LIMPOPO**

3. Full name, surname and qualifications of project leader:

Mr Dzunisani Innocent Baloyi

B.A. (Criminology and Psychology)

B.A. Honours in Psychology

4. List the name(s) of all persons (Researchers and Technical Staff) involved with the project and identify their role(s) in the conduct of the experiment:

Name:	Qualifications:	Responsible for:
Mr Dzunisani Innocent Baloyi	B.A. (Criminology and Psychology)	Research
	B.A. Honours in Psychology	

5. Name and address of principal researcher: Dzunisani Innocent Baloyi: P.O. Box 4124; Giyani; 0826

6. Procedures to be followed:

Exploratory interviews will be conducted using a schedule constructed from semi-structured guide questions.

Informed consent will be sought from each participant.

7. Nature of discomfort:

The interview could trigger emotional reactions including anger, anxiety and depression due to recollection of unpleasant experiences. Affected participants will be referred to clinical psychologist for intervention.

8. Description of the advantages that may be expected from the results of the study:

a. The study will improve the experiences of students with albinism in the University of Limpopo by generating awareness about their challenges in a university context.

b. Through catharsis, the interview will relieve the participants' distress and improve long term psychological health of students with albinism.

c. The study will expose environmental dynamics that lead to social and academic difficulties faced by students in the University of Limpopo. The information obtained will then serve as the basis for appropriate interventions

Signature of Project Leader: **DI Baloyi**

5. INFORMATION FOR PARTICIPANTS

PROJECT TITLE: THE SOCIAL EXPERIENCES AND ACADEMIC CHALLENGES FACED BY STUDENTS WITH ALBINISM AT THE UNIVERSITY OF LIMPOPO

PROJECT LEADER: Mr Dzunisani Innocent Baloyi

1. You are invited to participate in the following research project: **THE SOCIAL EXPERIENCES AND ACADEMIC CHALLENGES FACED BY STUDENTS WITH ALBINISM AT THE UNIVERSITY OF LIMPOPO**
2. Participation in the project is completely voluntary and you are free to withdraw from the project, without providing any reasons, at any time.

3. It is possible that you might not personally experience any advantages during the project, although the knowledge that may be accumulated through the project might prove advantageous to others.
4. You are encouraged to ask any questions that you might have in connection with this project at any stage. The project leader and the researcher will gladly answer your questions. They will also discuss the project in detail with you.
5. It may be that you feel discomfort when discussing your social and academic challenges in the university. However, I will ensure that it is discussed properly and if you do find that you have any problems (such as feeling traumatised, angry or depressed) after our interview I will ensure that you have proper referral to a professional counsellor/psychologist. The advantages of talking to me may be that you may be better able to relieve your distress and discuss your challenges in a safe and confidential environment. The research may also help other students in the same position as well.
6. Should you at any stage feel unhappy, uncomfortable or concerned about the research please contact Ms Noko Shai-Ragoboya at the University of Limpopo, Private Bag X1106, Sovenga, 0727, tel: 015 268 2401

SIGNATURE OF PROJECT LEADER: **DI Baloyi**

APPENDIX C: TREC (TURFLOOP RESEARCH ETHICS COMMITTEE) ETHICAL CLEARANCE



University of Limpopo
Department of Research Administration and Development
Private Bag X1106, Sovenga, 0727, South Africa
Tel: (015) 268 4029, Fax: (015) 268 2306, Email:Abdul.Maluleke@ul.ac.za

TURFLOOP RESEARCH ETHICS COMMITTEE CLEARANCE CERTIFICATE

MEETING: 02 November 2017

PROJECT NUMBER: TREC/395/2017: PG

PROJECT:

Title: The social experiences and academic challenges faced by students with albinism at the University of Limpopo
Researcher: DI Baloyi
Supervisor: Prof K Nel
Co-Supervisor: Dr Setwaba
School: School of Social Sciences
Degree: Masters in Criminology and Criminal Justice


PROF. TAB MASHEGO
CHAIRPERSON: TURFLOOP RESEARCH ETHICS COMMITTEE

The Turfloop Research Ethics Committee (TREC) is registered with the National Health Research Ethics Council, Registration Number: **REC-0310111-031**

Note:

- i) Should any departure be contemplated from the research procedure as approved, the researcher(s) must re-submit the protocol to the committee.
- ii) The budget for the research will be considered separately from the protocol.
PLEASE QUOTE THE PROTOCOL NUMBER IN ALL ENQUIRIES.

APPENDIX D: TRANSCRIPT OF THEMES

1. How would you explain the condition of albinism?

Participant 1: it is lack of pigment melanin in the skin and the eyes (¹ *lack of melanin*).

Participant 2: They say it is a lack of pigment melanin in the skin and eyes and the hair. It makes the skin pale, and the eyes become short sighted and the hair produces white and gold (¹ *lack of melanin*, ² *impaired vision*).

F: do you guys know the different types of albinism?

Participant 3: I don't know them I just heard of them.

Participant 4: I think they have said it all

Participant 9: I don't have melanin, but that question is for those doing science (¹ *lack of melanin*).

Participant 7: I'd say its caused by a mutation of genes, where the gene responsible for generating melanin is either absent or there's a disorder somewhere there. Ya that's what I can say because that's where it starts (¹ *mutation of melanin gene*).

Participant 10: I'd say albinism is a condition where the person lacks the pigment of melanin (¹ *lack of melanin*).

Participant 8: id also say that it's a condition where by there's little or no melanin and that results in the skin being light and susceptible to sunlight, you can burn easily and your eyes, they are very very very short sighted (¹ *lack of melanin*, ² *impaired vision*).

Participant 13: it is when the skin is pale and normally it becomes easily burned by the sun.

Participant 16: I think it is a condition of the skin of which the skin lacks melanin which is responsible for the colour of the skin, and it protects the skin from being burned by the sun you see (¹ *lack of melanin*).

Participant 14:: it is a condition whereby a person lacks melanin and the skin becomes very sensitive to the sun (¹ *lack of melanin*).

2. How did you feel growing up with the condition?

Participant 2: first of all I felt side-lined, I felt like I had to prove that I can do it so that I can affiliate with my people at school or at university I had difficulty more on the social side

because at university you live there and attend there (¹ *Discrimination*, ² *negative attitude from peers*).

F: did you apply to all universities or specifically this one?

Participant 2: no, there are many others

Participant 1: As for me, during my early childhood I felt so alienated, but at a later stage I attended school and people began to understand more about my condition and they, I got used to them. I went to public school myself, growing up there was more of tension (¹ *Discrimination*).

F: how would you describe alienation?

Participant 1: it is being separated.

Participant 3: for me growing up with albinism I didn't have challenges. I didn't feel like I'm different you see, because I wasn't the only albino in my community. Even when I went to school, I went to a special school, so I didn't encounter challenges just because I'm an albino (¹ *Discrimination*).

F: what kind of special school was it?

Participant 3: it was a special school for the blind and the visually impaired, the experience was good because we were all the same so I didn't feel somehow but when I went home, let's say during the holidays, because I was used to staying with albinos, when I went home I felt like I'm not like other people (¹ *negative attitude from peers*).

Participant 1: I have a question for her, so how did you feel when you came to university?

Participant 3: I knew that I would meet people like me, but then I never thought about it to social life and all, attending, because I was used to attending with people who were like me so when I attended with people who are different, I asked myself how it was going to be like.

Participant 6: growing up it wasn't bad like I didn't feel like I was different from others because I'm well going and my friends were not albinos. They took me like I was the same as them (¹ *Discrimination*).

Participant 9: I myself felt special because almost everyone in the community wanted to be with me, that's all I can say and every time I walked in the community, some strangers would call me to say hi, and ask about my condition and I appreciated the fact that my community

was not that ignorant. They always called me when I walk just to ask about my condition and when I listen to other students and their stories they are different from mine and some people would even buy me sunscreen (¹ *Myths and misconceptions*)

Participant 8: for me it was a bit challenging because I started to attend mainstream school before I went to boarding school and it was difficult for me to even focus in class because I didn't know that I was different from other people and I'd sit at the back of the class because I felt that I could see because if other people could see why wouldn't I see because no one ever explained to me that I'm short sighted and on the streets it was very difficult because people who I was not close to like some strangers would say to me 'legowa' or 'leswetle' and some would spit out because they were told when you see a person with the condition you must do certain things so that later on in life you don't have children with the same condition so for me it was not that pleasant until I went to boarding school with people who were like me (¹ *Name calling*).

Participant 7: for me I'd say people with albinism are the strongest people I know because as a child you grow up with people calling you with names but then you continue living, in other words I can say we are now stronger when we younger than we were now because now when someone calls you with names the anger is too much compared to when we were young like of course we'd get angry but it would be something that passes maybe because we were still kids but for me growing up I appreciate the fact that this whole thing of being called with names made me the strong person I am today because of the challenges I faced in society and at school every time I face something like that I tell myself if I could face it as a child I can continue to handle it. Ya it was difficult but I was the most intelligent in class and that gave me confidence and it made them respect me but then going to boarding school made things easier because there were people with same condition as mine (¹ *Name calling*, ² *Discrimination*).

Participant 10: for me I think it was different, it was okay. Actually most people didn't question like why are you like that like people wanted to be around me. Even this thing of calling names like 'legowa' for them it was not discriminating because they wanted to be around because of my colour you see, so I even attended public school because it wasn't tough for me to go to special school even the teachers were okay (¹ *Name calling*).

Participant 9: on that note of being called with names, one thing I've noticed is that in the community is that those who called me with names were children not adults which taught me

that little knowledge or no knowledge at all is a dangerous thing because all adults even when I touch down today they still treat me as their golden boy. They need to educate the children (¹ *Name calling*, ² *adequate awareness*).

Participant 8: I think the most painful thing is when you see a child walking with a mother or a father and that child calls you with names and that parent says nothing and you are busy walking there that hurts you so much. So I think if it was possible that communities could be educated and all of them adults and children that these are people as well and that we are African like them so there's no difference between you and them so (¹ *Name calling*).

Participant 9: ya I agree with you. The environment you grow up in plays a major role in our input (¹ *Adequate awareness*).

Participant 15: when I was growing up, for me, I think maybe it's because I was still young but it was okay, I was aware that I was different because I wasn't allowed to do everything that other children were doing you see. So I did feel different but I think it didn't affect me that much because I was still a child (¹ *Discrimination*).

Participant 15: it was not nice at all, people would call me names and it hurt and it made me feel uncomfortable (¹ *Name calling*).

Participant 18: for me it was okay only when I was at home, my family made me feel comfortable but the community would call me names like mukhuwa (¹ *Name calling*).

Participants: most people at school use to isolate me and it was very painful (¹ *Discrimination*).

Participant 11: It was difficult because I had to be careful about everything. When it's hot its either I stayed in the house or I made sure that I wore long sleeve clothes which was a bit difficult but the people were okay, they didn't call me with names and stuff.

3. What do you need, in everyday life, in order to minimise problems associated with albinism?

Participant 3; for me I need my hat because my skin is very sensitive, 10 minutes in the sun and it becomes very red. My sunscreen and my sunglasses (¹ *Protective clothing*, ² *sunscreen*, ³ *spectacles and sunglasses*).

F: is sunscreen expensive?

Participant 3: very expensive

F: isn't it something that you feel should be provided for free in the university?

Participant 5: sunscreen is very important, our skin is not the same, some get burnt by the sun fast fast, some late, for me the sun burns late because when I was young growing up they had been using these things on me from the start, things like aquas, I didn't do them and then to protect ourselves from the sun, we need umbrellas, hats. Yes and then for us they had been giving us sunscreen for free and we didn't get burned (¹ *Sunscreen*, ² *protective clothing*).

F: so the special schools you guys attended provided sunscreen for free?

All: yes (¹ *Sunscreen*).

Participant 4: there's an organisation for people with albinism that provides sunscreens, they used to give us sunscreen for free, it is called Albinism Society of South Africa. They used to provide packs of sunscreen and sunscreen for our lips (¹ *Sunscreen*).

Participant 1: the consequences of not complying with these sunscreens it causes skin cancers and skin damage (¹ *Sunscreen*).

F: do you think that a student who doesn't have sunscreen would not go to class?

Participant 1: Sometimes, because the sun from Limpopo is very hot. When I came here my skin wasn't like this. It affected me a lot, yes (¹ *Sunscreen*).

Participant 5: before coming here, how was your skin?

Participant 1: it wasn't this red.

Participant 2: ya, I think another thing is with the spectacles they make here at school, they want to zoom things, and with our condition the problem is not that we can't see far, for that one they cannot change, for us we need dim, we don't need zoom because we don't need too much light (¹ *Spectacles and sunglasses*).

Participant 5: and the spectacles are for seeing well when you are near (¹ *Spectacles and sunglasses*).

Participant 1; if we are lacking pigment, the lack of pigment simply means that we have too much access to light. Our eyes can easily access too much light (¹ *Lack of melanin pigment*).

Participant 3: and lipsun, it is a balm for our lips, it is very expensive at clicks and it treats us well and it is very small (¹ *Sunscreen*)

F: so students can't afford it?

Participant 4: obviously

Participant 7: an umbrella, with a dim colour and not a bright colour because the sun will damage my eyes obviously, I need spectacles for reading and I need sunglasses to avoid the sun (¹ *Protective clothing*, ² *spectacles and sunglasses*).

Participant 12: and I think I need to wear long sleeve clothes but that's not my style, you can't be always wearing long sleeve clothes and sunscreen. What else? Also large printed texts for my books any paper size is okay (¹ *Protective clothing*).

F: some spoke of a lipbulm for the lips?

Participant 9: it is like sunscreen for the lips we use it on a daily basis (¹ *Sunscreen*).

F: do you think these should be provided for free?

Participant 9: what do you guys think?

Participant 7: ya I think they should because it is not everyone who can afford it. (¹ *sunscreen*)

Participant 9: so my question is should they provide for all of you or those who are in need, those who can't afford? (¹ *sunscreen*)

Participant 8: no, what I want to know, because recently we were applying for disability grant so if we are telling the campus to help us apply for disability grant and at the end of the day we also ask them to give us sunscreen and these things then what are we saying? What are we using the money we get for? (¹ *sunscreen*)

Participant 7: you know, as RDC students right, there are those who have bursaries and that other one what do we call it? Yes then some of have to pay for our fees and have to use these SASSA grants, I have to buy food for myself, its cold I need jackets, what else? Sunscreen is expensive, so for those who are disadvantaged it can work for their advantage. The reason I'm saying this is that those who are not in need should be taught that lesson of responsibility. That we should not always cry for help. The advantage with us is that we are a very small group, it's not easy to like lie when it's a small group, and one can deal with a small group.

People would know that you have this and you don't have this so I think it would be much easier. (¹ *sunscreen*)

Participant 12: sunscreen. We need sunscreen but it's very expensive (¹ *Sunscreen*).

Participant 14: I need sunscreen that's the one thing we use every day to protect our skin from the sun because our skin can burn easily (¹ *Sunscreen*).

4. Have you ever experienced any social difficulties that you relate to your condition?

Participant 1: yes, as for me, I think it's a personal thing, sometimes I feel I am afraid to raise up my hand in class because people would be looking at me and that I couldn't cope in crowds. I don't usually be myself in crowds, I cannot participate in class and sometimes during presentations I don't have that much confidence or self-esteem.

F: so is it okay to call people with albinism "albino"

Participant 3: for me I don't have a problem, I understand that some people call us albino but I'd really love people to stop calling us albino. I don't have a problem but if they can stop its something I'd really love that (¹ *Name calling*).

Participant 1: as for me I have a serious problem with it. I grew up not being called such things. They called me by my name (¹ *Name calling*).

Participant 5: I love 'legowa' (¹ *Name calling*)

F: literature suggests that it is more appropriate to use people with albinism

Participant 1; Yes that one is more appropriate but I think calling me by my name would be better (¹ *Name calling*).

Participant 3: even in class hen we arrive late oh my God! The attention (¹ *inappropriate looks and/or staring*)

Participant 1: as for me, im good with socialising with people so everyone in my school was friend, everyone knew me like a friend so like I had no problem socialising with people. I had a good relationship with my teachers, community members. Everyone.

Participant 6: I have a problem with people calling me by names such as 'mlungu' or makhwetla (¹ *Name calling*)

F: so if a person is close to you do you have a problem with name calling?

Participant 6: no, not really, also children I don't mind (¹ *Name calling*)

Participant 4: not just everyone, even at high school I wouldn't mind someone who knows me but not any random person I feel insulted (¹ *Name calling*).

Participant 2: another problem is it creates trust issues between you and your family or community members like you ask yourself what does this person want?

Participant 3: and then the community, isn't it people with albinism are short sighted, let's say I'm walking there at kasi, and then elderly people are sitting and I don't see them then I pass them, they think that I don't have respect why don't I greet them and they don't understand that I can't see them so people think you're a bad person or you think you are better of yourself and you want to be alone (¹ *Impaired vision*).

Participant 7: ya it happened sometime youd ask someone where can you find this, where can I finf this shop? Youd greet people and they would not reply and you get unpleasant looks from people. It wasn't easy because youd be reminded that im not the same as everyone, this means im different but what made it better is that we are many and most of us are from the same school so we knew each other which made things easier (¹ *Discrimination*, ² *Inappropriate looks and/or stares*, ³ *Myths and misconceptions*)

Participant 10: ya to add on that one of unpleasant looks, some people can make you feel like theres something wrong with you. Whenever you are passing people will be looking at you like theres something wrong. That one I experienced in some places and not from my place (¹ *Discrimination*).

Participant 8: about a month ago, I was at pick n pay and there were these 2 guys, so they came to me and they to me we need your help with something, and I said no I cant help you because you know you can't just help everyone so they wanted me to pay for their things do I said no I don't have the money and then they said you can fuck off because people say these about you and we will help them cursing you so I was like surprised like what's wrong with these people? (¹ *Discrimination*, ² *Myths and misconceptions*)

Participant 9: I think it depends on the kind of people you meet on a daily basis. For instance, I once got into a taxi and this other lady couldn't sit next to me so basically I went to the back seat so ya I didn't feel bad because I cant change who I am or my condition, its natural, its me, its who I am. So I used to be depressed about it but then I realised its just lack of

knowledge, instead of attacking them I should be the one to educate them about my disability and my condition (¹ *Myths and misconceptions*, ² *Discrimination*, ³ *adequate awareness*).

Participant 7: ya for me there was this lady and she had a scarf and I asked her if there is someone next to her and she didn't reply so id decided to sit there and she took her scarf and covered herself, imagine from Polokwane to Burgersfort and then when we got there we got into another taxi to Nelspruit then she approached the taxi and it was full so I was like a little happy (¹ *Myths and misconceptions*).

F: lucky have you encountered a situation like that?

Participant 8: no I've never had such a situation to such a point where I got into a depressive state.

F: how do you deal with your social experiences?

Participant 8: I just tell myself its best to just ignore them because it's like this every time

Participant 9: for me also parents are also very protective, like they always forced me to wear long sleeve shirts and when it's very hot I was forced to call my friends to come over so we can play in the house (¹ *Overprotective parents*).

Participant 7: for me I still use the same sunlight green bar my mom won't allow me to use another brand. This is because when I was young my skin would be reactive to other bar soaps so she still sticks on that. She checks if I'm still using the right lotion and if I still have sunscreen and keep me from going outside when it's hot. They don't send me anywhere when it's hot and now they won't allow me. Growing up they expected me to wear long sleeve at all times but I would cut them and we would fight because of that (¹ *Overprotective parents*).

F: have you ever experienced any discrimination?

Participant 7: I remember in my first year we had to get our scripts back and some guy behind me saw my scripts and he said sisi, is that your script, and I said yes and he said no it can't be yours, it can't be. And with group assignments, wed struggle to get a group and no one wanted to be in our group because they thought we are slow learners. At church as well, ive always had to prove myself that I can do it as well, even at home and at school I always had to prove myself that I'm also capable, I'm good at singing, look at me (¹ *Discrimination*).

Participant 9: this one I think we face the same challenges, on that one of finding groups when we are doing group assignments, it's difficult (¹ *Discrimination*)

Participant 11: the other thing is that they call us with other names (¹ *Name calling*)

Participant 12: even making friends can be difficult, say in class they say there must be groups then you don't get to choose who you want to be with because I am afraid to approach them because they might reject me. Then I realised that just because I am an albino people think that even intellectually we don't function properly (¹ *Discrimination*).

5. Have you ever experienced any discrimination because of your albinism?

Participant 2: almost everywhere, because if they look at you they think you are not capable of doing somethings so it becomes a challenge for me that I have to prove to you that I can do it and somewhere somehow it ends up hurting me or giving you a perception that like albinos don't understand so well and end up doing something in a great measure then someone will say that we don't understand but I was trying to show that person that I can do it (¹ *Discrimination*).

Participant 4: for me even applying for university I did not have thought of what what or discrimination (¹ *Discrimination*).

Participant 2: there's also the issue of negative talk like maybe you arrive at a place and you can see the looks that we take ourselves as being better because we can't socialise with them so you going to be on the other side and when it comes to other people they look at you in a different way, they have certain comments. Let's say you are in a clinic you are sick, someone who works there can work with everyone else while you are there, they can't do anything or talk to you because of some certain beliefs I don't know why (¹ *Inappropriate looks and/or stares*, ² *Discrimination*, ³ *adequate awareness*).

Participant 1: to add, okay to add on that it starts with our government because there are certain occupations that occupy people with albinism and they'll say no they are trying to protect us blah blah blah, for example, working in the sun or being exposed to the sun, yes they are protecting us but somewhere somehow they are discriminating us before we can go to what people think or do. When we grow up our parents are overprotective of us so it seems like they are limiting our space to explore and know things in the world (¹ *Discrimination*, ² *Overprotective parents*).

Participant 5: true. My parents don't allow me to go to school alone (¹ *Overprotective parents*)

Participant 5: even me, even though I'm this old, it's true. But at the end of the day I understand that it comes from a good place and they just care about us so I understand (¹ *Overprotective parents*).

Participant 3: if im out for a long time they will send someone to look for me, myself honestly I feel like myself when I'm here at school with my peers but then at home you become that person and you are guarded (¹ *Overprotective parents*).

F: do you feel their fear is reasonable?

Participant 3: I think their fear it's reasonable (¹ *Overprotective parents*).

Participant 5: though at home they overdoing it but I understand (¹ *Overprotective parents*).

Participant 1: as for me im not under supervision I can go anywhere (¹ *Overprotective parents*)

F: do you think it differs between males and females?

Participant 4: I don't know but there was this time they wanted to send us for an errand around 6 in winter and I was left behind because im albino and its late and it for me it did not treat me well because I like to be free (¹ *Overprotective parents*).

Participant 2: what I'm concerned more about is, is it more in males or in females?

Participant 1: from experience wena were you allowed to go anytime?

Participant 2: for me I think its gender wise because with females I don't think they can take care of themselves better than a guy (¹ *Overprotective parents*)

Participant 6: me sometimes they protect me, they don't allow me to go around with people they know or trust (¹ *Overprotective parents*)

F: so its more about fear and trust?

All: yes

Participant 8: for me when I was still in primary, I passed my grade 3 and then they said I should go to princehoff, and at princehoff they said I did not pass well my grade 2 and if I come here they would take me to grade 2 so I won't progress to grade 4 then I went back to mainstream school and I did my grade 4. I failed my grade 4 because I wasn't coping and the

teachers at the board did not care and then I went to Bosile and I did my grade 4 there and my performance started to improve and then I passed my grade 4 (¹ *Discrimination*).

F: would you say it was the environment that affected your performance?

Participant 8: yes, because there I was with people who understand my condition so I could get to the board and no one would say anything (¹ *Discrimination*).

Participant 7: with me I did my preschool at mainstream so the challenge was that I could not see at the board that's the challenge I can say stood out but my performance at least was good because at least the teacher understood, so during break time she would ask that I remain so that I can check if I did everything (¹ *Impaired vision*)

Participant 13: Ya, eish I don't know why but people look at you like you are half human hey, we are just as competent and able to do what normal people can do but most of the time no one believes in us enough to give us a chance (¹ *Inappropriate looks and/or stares*, ² *Discrimination*).

Participant 15: I agree with you, there's a lot of pressure for us to prove ourselves you know, I always feel like I have to go an extra mile to be successful. Even at school, I've always had to push myself to show that I can do it too (¹ *Discrimination*)

Participant 16: I haven't experienced any discrimination directly but I know that albinos are always treated differently out there, at school and in some communities it's the same (¹ *Discrimination*).

6. Have you ever experienced any academic difficulties that you relate to albinism?

Participant 1: yes, albinism it accommodates with partial blindness so you can agree with that people who attended public schools they could not see very far like, so the chalkboard, the distance between me and the chalkboard. Just to add people with albinism are a little naughty they don't really listen in class, they make fun, they are involved in the moment of fun. As for me, I wasn't really listening I was a noisemaker, a troublemaker, boss of my crew. Imagine me I was an albino with a group of normal people so fortunately I had a cousin whom when I got home id go to catch up and I had a good memory so it's a lie that albinos are not intelligent, these are the smartest people but they are lacking the opportunity to access to things through their physical ability but fortunately we made it (¹ *Impaired vision*).

6. Have you ever experienced any academic difficulties that you relate to albinism?

Participant 9: yes I do and one thing I hate is that when we are drinking, it's like they feel pity for us when we do what is normal to them, they are surprised. It's like they don't believe that someone with our condition can drink, can do what they do, but we do and some of them are so understanding (¹ *Myths and misconceptions*).

Participant 10: yes I do, and I can say that the people I'm with around the campus are so understanding and supportive all the time and I think that keeps me going all the time because they don't take me as if I'm disabled but they all so supportive like I'm normal like them. They don't call me with names and stuff (¹ *Name calling*, ² *Discrimination*)

Participant 9: I think it all depends on the kind of relationship you have with that person if you are not in good terms with that person and they come and say those things, you can just send them to all to hell.

Participant 11: Yes when I can't see properly and want to seat in front but you find that there's no space (¹ *Impaired vision*).

Participant 12: I went to special school for the blind and visually impaired, it was easier there, were got free sunscreens, and we could see in front, so ya it was fine I like that the people there were understanding of our condition and they helped us a lot. The teachers there were very understanding (¹ *impaired vision*, ² *sunscreen*).

Participant 13: Another thing is that while I was still at mainstream school, the challenge for me I didn't feel like I was part of the people there I had friends but some did not understand me and it was difficult for me to socialise. But then when I went to special school there was a lot of albinos and I felt like part of family (¹ *Discrimination*).

Participant 15: I attended both special and mainstream and at mainstream school it was difficult, sometimes I could not see at the board even when I'm in front (¹ *Impaired vision*)

7. Do you socialise with peers that do not have albinism at the University?

Participant 1, 2, 3, 5, 6: yes

Participant 4: for me no (¹ *Negative attitude from peers*)

Participant: yes but they are very few, very few.

Participant 4: most people are just my classmates and we don't often meet it's a matter of the phone. We chat

F: what do you think is the reason?

Participant 4: ey, I don't know like I don't know maybe it's from me, you see if I didn't attend with them then id teach myself to socialise (*¹ Negative attitude from peers*)

Participant 5: okay I don't know if it's because I'm an albino and I isolate myself or I'm not good at making friends so I'm used to people approaching me than me approaching them so right because I always with this one (*¹ Negative attitude from peers*)

F: is this a common thing for you all?

Participant 1: no, as for me, when it comes to interpersonal relationships, I can make friends a lot, with the case of being in general like ordinary high school and primary school I, the first thing around university, fortunately there are people who are from the school or village that I come from I could talk to them before I could get used to people from DSU, 2015 the year I came here I could socialise with people from outside, my best friend is not from people from DSU so socialising is not a problem with me. I'm just demonstrating that socialising with me is not a problem with me. Ya every classmate or every person knows me yet I'm not talking to them but through conversations with them they can get that interest that I'm not an introvert (*¹ Negative attitude from peers*)

Participant 2: I think that one of socialising with people who are not with albinism, I think it also depends on your environment, which school are you coming from, let's say they went to school where albinos are a lot you see but then if you went to a public school then you are exposed to many people (*¹ Negative attitude from peers*)

Participant 4: plus you see us from the same school we are always together most of the time like even that need to have friends from outside is not there because my peers are always there. (*¹ Negative attitude from peers*)

Participant: even me I don't like to be around people who don't understand me, my understanding is that I don't have friends who are not albinos because let's say I'm your friend and I'm used to you, I won't be comfortable around your friends because they won't understand me. I don't want them asking me too many questions. Okay I understand that I'm

the one who is supposed to tell them, teach them so that they understand me but then again they don't understand me. (¹ *Negative attitude from peers*)

Participant 1: to criticise on that I think it might cause an impact in the future in situation where you are being forcibly grouped with people you are not used to in class. For instance, a lecturer decides to pick up a list and form a group, such people will face difficulties when it comes to socialising with others and it can affect their performance hence in work places (¹ *Negative attitude from peers*).

F: how is it when you have to do group work?

Participant 3: for me Sphe is my classmate so we are always in the same group

Participant 4: in a group of 5 it's always 2 and others

F: so how do you relate with others?

Participant 4: ah shame. we do

Participant 3: we are talkative you see, so when we are together I am comfortable around Sphe. It's easy because when I'm alone around people who are normal I am not myself but Sphe knows me she understands me, even when I do crazy things we do them together.

Participant 1: so I have a question towards her, so how will you cope when you are randomly like you are grouped by the lecturer? I once came into a situation like that but fortunately the people whom I was in group with were extended students and my best friend was one of them so I'm asking on your behalf since you are only used to Punkey and (¹ *Negative attitude from peers*)

Participant 4: no, I think I will cope like my classmates they understand me like even though we don't interact like whenever we meet they understand that I don't see well and stuff I won't be 100% but I won't be distant I'll be able to fit in because some I know (¹ *Negative attitude from peers*)

Participant 5: so what about people you don't know, let's say in a psychology class?

Participant 4: yoo I don't know (¹ *Negative attitude from peers*)

Participant 3: I am of the understanding that okay, in some situations isn't it I know, let's say they put me in a group of people who are normal and I know them I'll be okay you see, but then if it's people I don't know, I'll understand that this thing I have to do I'll put aside the

fact that these people don't understand me and I'll do what I have to do (¹ *Negative attitude from peers*).

Participant 10: Yoooo, I do socialise, okay mostly with classmates but I have to be honest, when I got into the campus I was scared to socialise with people but as time went especially with people im studying with (¹ *Negative attitude from peers*)

Participant 14: I socialise mostly with people from here at DSU you see, because these are people who understood my disability first, I socialise a lot with people with albinism though because some I knew them from before, some of my peers we live at the same res so it is easy to talk to them and visit them but it depends because its not easy to socialise with some people (¹ *Negative attitude from peers*)

8. What have your social experiences been like at the University?

Participant 2: at the university it started being low, like people who are coming from Kwazulu-Natal, Mpumalanga they started off discriminating people with albinism so when they get here they still do the same thing because they don't have the understanding but then the experience gets to be better when you have this friend and then you explain to them and maybe they have other friends, if they ask them that why are you with that person they can explain to them maybe they will be able to understand you and then you have a good life (¹ *Discrimination*, ² *negative attitude from peers*).

Participant 3: my social life has been good because I got here and I was people I was used to and Sphe was there and I didn't need to have friends from outside because I didn't need them as I have these ones.

Participant 6: for me it was not bad because like when I came here I was with some of my friends from home so that was easy for me (¹ *negative attitude from peers*)

Participant 1: as for me, I'd like to say something, to do something and feel comfortable about it I first understand the situation that for instance the word university. It's just the 2 words, unity and diversity, it means that people who are different they are united and combined together so you have to understand that we are people with different perspectives so we have to understand that people and they tend to judge so what we have to do is to find out a way to adapt to the environment so that you are not affected academically and socially (¹ *Discrimination*, ² *negative attitude from peers*).

Participant 10: For me it has been good, I have friends who I socialise with although most of them are people from Rea Gona (DSU), ya it has been good

Participant 12: I wouldn't say I am always socialising with other people because I like my own company most of the time but I also have friends mostly classmates and people I'm staying with at res but mostly I prefer to be alone (¹ **Discrimination**, ² **negative attitude from peers**).

Participant 14: Eish, nna my social life is with people with my condition because I feel like others won't understand me and it can be hard making friends with them (¹ **Discrimination**, ² **negative attitude from peers**).

9. Do you feel your peers (non- albinos) accept you? If you do (or don't) explain why.

Participant 5: I think they accept me you see, because there are some people, okay say you are my friend but you don't want to be seen in public with me just because I'm albino because yourself that what are people going to say but then my friends accept me. They go with me everywhere even when we go off campus they are not ashamed of me like I don't feel different when I'm with them (¹ **Negative attitude from peers**).

Participant 2: I would say that one I'm not sure, because it comes back to the social issue that you don't know that the person, is he or she your friend because they don't want to queue at Shoprite or because they want to get somewhere so I think they accept us with reasons like they have something to get (¹ **Discrimination**, ² **negative attitude from peers**).

Participant 1: as for they accepted me because at first year I didn't have my peers, my classmates I don't think they really accepted me I don't know because they were from different communities and they got matured and understood me and studied me and everything and I think now we are fine with my peers. I have a best friend who is not an albino he's like a brother to me (¹ **negative attitude from peers**).

Participant 4: they accept me, like I feel good because they want to be close with me even when I'm not interested. They call me showing that I interest them they accepted (¹ **negative attitude from peers**)

Participant 7: they do accept me because if they didn't accept me they wouldn't be my friends, they wouldn't be my peers. As I mentioned earlier on that if I see some attitude I walk away (¹ **negative attitude from peers**)

Participant 8: I think they do accept me because if there's something they come to my room, they tell me lets go to K block, let's go check your semester mark because we are also going there so I think they do accept me, they understand (¹ *negative attitude from peers*).

Participant 9: with me they understand to such an extent that when it comes to things like checking marks they won't even call me because they know that I'm short sighted so it's useless going there so I always ask my lecturers to post the on blackboard because I can zoom and stuff so with my friends they'll just go and they'll call to say we are here, we are busy checking semester marks give us your student number we will send you everything. Sometimes when it's too hot they say don't worry we will do everything (¹ *negative attitude from peers*)

Participant 10: I can say yes because they enjoy my company even when I'm not there they ask Zach where are you (¹ *negative attitude from peers*).

Participant 16: they accept me, some of them just introduce me to their friends and tell them my problems (¹ *negative attitude from peers*).

Participant 15: Yes they accept me because in class they greet me and some are my friends we communicate on WhatsApp and other social media (¹ *negative attitude from peers*).

Participant 18: I think they do accept me because most of them haven't showed me any signs of hate although all over the campus sometimes when you are walking or at the cafeteria you see some of the looks you get I don't know if they are just interested in me or they are surprised to see an albino. But those I'm close to like my friends and classmates they accept me (¹ *Negative attitude from peers*, ² *inappropriate looks and/or staring*).

10. Do you feel your lecturers accept you? If you do (or don't) explain why.

Participant 2: some, some are annoyed that you are always knocking st their office for them to do something for you. There's this thing they print a large paper for us with a small font which is still the same as a regular paper with a small font whilst they can print as a bigger font on a regular paper even if its 20 pages with a big font its fine for us. So when you explain these things some of them can even hate you they don't want to see you and it becomes a problem with your marks because they remember that it's that one. Sometimes we write here (DSU) and when you go and inform them that I write in DSU some of them forget and when you go and remind them its like you think they are dump they don't know what they are doing (¹ *indifferent attitude from lecturers*, ² *impaired vision*).

Participant 3: I don't know if they accept us or not its like they don't care, he spoke about slides. They just do to get rid of you but its like they don't care about us (¹ *inappropriate attitude from peers*).

Participant 4: I don't think they care, they just do their job and move forward, every time you tell them you write at DSU you need to remind them constantly that every time they say there's a test you have to remind them (¹ *inappropriate attitude from lecturers*).

Participant 4: but some of them try. Some (¹ *inappropriate attitude from lecturers*).

Participant 3: yes, but very few (¹ *inappropriate attitude from lecturers*).

Participant 7: they are different, just like society, just like students. It all depends on how you take human beings so I had an experience with my economics lecturer she wouldn't care if I could see on the board or not and economics you know it has calculations, graphs and stuff and I expected so much of her so when we told that we can't see she at least you guys be in class, youll come for consultations she would just laugh and say you guys are lying to me, you can see. This other day she was lecturing something that would be on the question paper the following day and she wasn't concerned we cried tears and we went out of the class and one of my friends had to give up on economics so it depends because some of the lecturers are understanding we don't even struggle with them and they always bring question papers here (RDC) (¹ *indifferent attitude from lecturers*).

Participant 14: I would say that some do and some don't, I say some because some take the effort to understand our needs and like for example when we are writing a test they forget to arrange us that we write at DSU, but some you don't have to constantly remind them to bring question papers at DSU (¹ *inappropriate attitude from lecturers*).

Participant 10: I think they do because it's their job but it's not easy to say. I think they may accept us as students but do not accept our condition because most of them just they don't take our needs seriously. They forget to bring question papers at DSU and we have to write sick tests most of the time (¹ *inappropriate attitude from lecturers*).

Participant 15: I also think they don't care most of them but it's not all of them some make an effort shame (¹ *inappropriate attitude from lecturers*).

Participant 18: They do try, i think soe just need to be more aware that there are students with albinism even in the lecture halls they must try to care more so our lives can be easier like other students (¹ *inappropriate attitude from lecturers*).

11. Do you think that your albinism affects your ability to integrate into your peer group at UL? If yes (or No) explain why

Participant 5: as for me, yes

Participant 4: for me, yes.

Participant 5: I can't even forget that like when I'm like in a group form, it's not easy to feel like a normal person (¹ *negative attitude from peers*).

F: do you think it's your personality or something else?

Participant 1: I don't know they take it from my personality since I like being open to them they take me like a normal person (¹ *negative attitude from peers*).

Participant 3: I think it's my personality, I never felt different in any way. Like we grew up together but when I started going out there I can feel like I'm not like them. I feel that I have this condition. Ya so let's say there's a part to be a lab assisted I'm reluctant to apply because what if they don't take albinos like I feel they'll say she won't be able to help people because she's albino. That's how I feel (¹ *Discrimination*).

Participant 5: until you experience that you have to go there and not put yourself down (¹ *Discrimination*).

Participant 3: but it's not easy (¹ *Discrimination*).

Participant 1: it's just about confidence

Participant 9: I don't think it affects that because some of the people I hang around with they don't like ignore me, they can even come to me and ask for my opinion like what do you think? Like let's say we are discussing something in class like how do you see this? And how will you act? So I don't think it affects that like I think they believe in me (¹ *negative attitude from peers*).

Participant 7: for me I find it hard to approach some people because you know some take us like this, some call us that and some believe that if you talk to this one something will happen

so for me truly speaking it is hard to approach it happens to me often (¹ *Myths and misconceptions*, ² *negative attitude from peers*).

Participant 8: no like for me I think people find people with albinism interesting these days like because some, especially in my group, I remember this other time I didn't attend a psychology class and they gave us a group assignment and 3 group leaders approached and said, you know what, we really want you in our group because they gave us this and that so I was really excited about that, that we are being slowly accepted, slowly but surely (¹ *Discrimination*).

Participant 14 : for me I used to feel like I won't be accepted if I approach them until I realised that it's not them it's me, I'm just an introvert naturally but always when I approach them they don't have a problem with me. In fact, they enjoy company. Most of us fear rejection, we don't want to feel rejected so I feel if we deal with that fear, it will be possible for us we will not have a problem to approach anyone (¹ *Discrimination*, ² *negative attitude from peers*).

Participant 15: It does because some of our peers don't understand our condition so some may have a certain attitude which just offends you see (¹ *negative attitude from peers*)

Participant 16: For me also from my part I think it does in the sense that sometimes I may not feel comfortable around people because you are never too sure if that person will get you or they are just going to make rude comments so ya (¹ *negative attitude from peers*)

Participant 17: I do socialise a lot and so far I think it's all about your confidence and self esteem

Participant 4: there are just some who don't just understand. I once got hurt because someone in class thought I'm full of myself because she tried to talk to me and I ignored her, like okay, I didn't even see her and I didn't hear or see that it's her because I can't talk to just anybody. I don't know so just because I didn't see her she thought I ignored her and it hurt me (¹ *negative attitude from peers*).

12. Do you have any social challenges that you would like to discuss?

Participant 2: ya I think when we are interacting in the university I understand that we are not supposed to be called someone living with albinism but the fact is we are living with albinism so if we doing something like we are going to play soccer I need my hat and glasses when

I'm playing soccer I don't want anyone commenting in it so if we are like that they should also think about that like if we are going to the mountain if anything can just hurt me I can bleed very soon so those kind of things I can just say I'm not going to the mountain or I'm not going to play sport I think that can be a social problem (¹ *protective clothing*, ² *negative attitude from peers*, ³ *discrimination*).

Participant 1: I feel the same sometimes but as for me I don't separate myself, whatever they do, I do, like if I use the rule like the normal rules so I don't like to feel separated. I think about the risks but it does not hinder me (¹ *discrimination*).

13. Do you have any academic challenges that you would like to discuss?

Participant 5: I think it's just those ones we've discussed like when lecturers forget us (¹ *indifferent attitude from peers*).

Participant 3; even the lecturers, they should just understand that we cannot see when they come with their slides on the projector I can't see so like they must bring something in class for me like printed slides so that when they are looking at their slides I'm also able to look here because I can't see at the projector and then the minute I can't see what's on the projector I lose concentration so at let them make something so I can be able to see and then I am able to follow at the same pace (¹ *indifferent attitude from lecturers*, ² *impaired vision*, ³ *adequate assisting devices*).

F: do you think it affects your potential to do greater than you are doing?

Participant 3: yes, if I can't see on the projector like it affects that module because from there even the English you are speaking for me I just go to class just for the lecturer to see me I just fail nonetheless (¹ *impaired vision*, ² *adequate assisting devices*).

Participant 7: I don't know if this is a challenge, I'm a Christian myself, I fail to understand why Christians behave like they don't know GOD. That thing of we being discriminated by Christians in church I fail to understand because we don't speak at the same level but as a child of God automatically you accept people for who they are before you even open scriptures automatically as human beings but then it goes deep as affecting Christians (¹ *Discrimination*).

F: is the discrimination that you are talking about just in the church or outside church as well?

Participant 7: there is discrimination but my biggest problem is at church like people who know we are all created by God they read that scripture everyday but then (¹ **Discrimination**)

Participant 9: I won't say I have a problem anymore like after that depressing state my apologies for the language but I have that attitude that if they don't accept me fuck it and go to the next person (¹ **Depression**).

Participant 10: for me what makes me not to mind what they are saying is studying psychology, I think that encouraged me like some of the theories like behaviour theory and cognitive therapy make me not to care because they encouraged me.

The issue of names, I mean that very hurtful because even though I'm older I think people just need to understand that people with albinism are also people and should be treated with respect (¹ **depression**).

Participant 14: Also I think if other students can like not stare at us when we are busy with our business that would be a good thing because it causes me to think maybe there's something wrong with me I think it can also make easy around the campus (¹ **Inappropriate looks and/or staring**).

Participant 16: Yes and like I have a difficulty participating in things like sport because I need to be careful to not injure myself and I have to protect myself from like the sun when it's hot so I can't really do some of these things while wearing a hat and sunglasses you see (¹ **Protective clothing**).

13. Do you have any academic challenges that you would like to discuss?

Participant 5: I think it's just those ones we've discussed like when lecturers forget us.

Participant 3; even the lecturers, they should just understand that we cannot see spo when they come with their slides om the projector I can't see so like they must bring something in class for me like printed slides so that when they are looking at their slides I'm also able to look here because I can't see at the projector and then the minute I can't see what's on the projector I loose concentration so at least let them make something so I can be able to see and then I am able to follow at the same pace (¹ **impaired vision**, ² **inadequate assisting devices**).

F: do you think it affects your potential to do greater than you are doing?

Participant 3: yes, if I can't see on the projector like it affects that module because from there even the English you are speaking for me I just go to class just for the lecturer to see me I just fail nonetheless (¹ *inadequate assisting devices*).

Participant 8: yes, sometimes you find that they didn't make a question paper for you and after that they tell you, even if you want to write, that no come on this day and see me in my office and when you come they tell you that because others have already written that paper we will make a new question paper for you and you find that they are giving you things that are different from what others have written so that's not fair (¹ *indifferent attitude from lecturers*).

Participant 9: ya that one is unfair, can you believe I wrote a sick test because there was no question ya large print when other student are writing and I wrote last week, a week before exams so it is unfair (¹ *impaired vision*).

Participant 7: for me I can't see on the board and it really hurts because you easily lose concentration, you can't focus when you can't see a thing on the board. The other students are able to focus because they are busy taking notes and when they ask questions they easily answer while looking on the board so I'm forced to listen and do nothing but listen and I can't write as fast as the lecturer is busy speaking. I remember this other time I asked the lecturer, sir can you please slow down because I have to write while listening to you and I can't see on the board and he said I'm sorry, I will. 5 minutes later on went back to the routine and he said that this is how I speak. So I was expected to understand instead of him understanding me because im the one with a challenge so for me that's my biggest problem. I find it hard to concentrate in class when I cant see anything (¹ *impaired vision*, ² *inadequate assisting devices*).

Participant 9: and on that one by next year it will become a university policy that the lecturers must provide that material 2 weeks before (¹ *indifferent attitude from lecturers*).

Participant 7: and we went to the SRC to suggest that can they tell these lecturers that can you bring these notes as they come to class. So that as they are busy doing calculations, when you say 3 okay, I can see where the 3 is you know, so that I go with you at the same pace and these lecturers say we want to outsmart the whole class because I will give you notes and then you study in your rooms and when you come to class the following day you are smarter than the rest. So are we supposed to be stupid than the rest? (¹ *indifferent assisting devices*)

Participant 11: I always have a problem seeing on the projector because I'm very short sighted so it is hard to understand what the lecturer is teaching so luckily I manage to pass my subjects but I think it becomes a disadvantage compared to other normal students (¹ *inadequate assisting devices*)

Participant 16: Sometimes it better to not go to class because even when I go there I can't see what the lecturer is talking about on the slides so I see it as being useless sometimes because I cannot concentrate. Some at least post the notes on blackboard but some don't really care about us so it's hard (¹ *impaired vision*, ² *inadequate assisting devices*).

14. What improvements do you think the university can implement in order to improve your social experiences?

Participant 3: let there be awareness campaigns so that people can know there are albinos in the campus because they don't understand so maybe if they can be made aware about our condition. Even though there are some awareness campaigns people don't attend like they don't care so for me because people don't care I just have the attitude that I don't care what they think about me even if they understand me or not I don't care I just tell myself that I just came to get my degree and leave (¹ *adequate awareness about albinism*).

Participant 4: that side of the library, I can't see those steps. They've been complaining about the matter even I came to the university (¹ *appropriate lighting*, ² *painted steps*).

Participant 1: there are also some by that side of admin like you have to torch there's no light there, next to the stuff cafeteria (¹ *appropriate lighting*).

Participant 4: the library steps need to be painted seriously not with a dark colour, something like yellow like even in the middle of the day it's just worse because the light is too bright (¹ *painted steps*).

Participant 2: the lecture halls, there needs to be bigger screens (¹ *adequate assisting devices*)

Participant 4: we can't see even when we are just sitting in front it makes no difference. That's why in class we get bored some of us like you just come out of the class because the lecturer will be explaining something on the screen and you find out that he or she didn't even read it (¹ *impaired vision*, ² *inadequate assisting devices*).

Participant 6: I think we just need more lights like where there are steps (¹ *appropriate lighting*).

Participant 9: I think we must have more workshops educating people about albinism and as DSO we agreed that next year we won't have an annual disability day, but an annual disability week because we believe that a day is not enough (¹ *adequate awareness about albinism*).

Participant 7: and as much as the health centre, isn't they know more about this thing, I believe they know more than we do, as much as they have awareness days for AIDS, STIs, STDs, pregnancy, sex whatever, I think they should consider this as well because they know very well that there are students living with disabilities in this campus, there are students with albinism in this campus so I think even them they need to take this into consideration (¹ *adequate awareness about albinism*).

Participant 8: I think they should put more emphasis in September, because its albinism awareness month because this year nothing much was done (¹ *adequate awareness about albinism*).

Participant 12: They need to paint the steps in colours we can see so it's not difficult for us to go around the campus at night and during the day because the sun affects our eyes (¹ *painted steps*, ² *appropriate lighting*)

Participant 14: And at night some of the steps are too dark so we they can put lights in those places. It's not us alone who cannot see those steps even normal students cannot see at night so more lights would help in those places (¹ *appropriate lighting*, ² *appropriate lighting*).

Participant 15: Yes more disability campaigns can help (¹ *adequate awareness about albinism*).

Participant 18: Students and lecturers must be educated about our condition and disability so that they can also stop some of the things like names and staring. I think if lecturer knew more about our condition then they would meet us half way by providing slides in class and stuff (¹ *adequate awareness about albinism*).

15. What improvements do you think the university can implement in order to improve your academic experiences at the university?

Participant 2: I think they should provide assisting devices in time before we fail because they wait for us to complain that we can't do this because of this they don't even do much (¹ *appropriate assisting devices*)

Participant 3: like we have to strike first

Participant 4: like now they only brought assisting devices because we had to strike for them (¹ *appropriate assisting devices*)

Participant 7: first of all, they have to listen to us because when we tell them about our condition because they decide for us, because even with the issue of assisting devices because right now I don't have spectacles I have a laptop, because they think a laptop can do much for us. I think that's the first thing that they should do because we are the ones who know more about our disability because he might have albinism, I might have albinism but our conditions are different so by listening to problems individually I think that can make a difference (¹ *appropriate assisting devices*).

Participant 9: Especially on the one of spectacles, we are being assessed by students who don't have full knowledge and sometimes they say their mistakes in front me, you tell me I forgot this and that but oh there's no problem, and its my life, that's me, we are being assessed by people who are drunk, who are high. They once admitted that in front that today I'm high, like really? (¹ *appropriate assisting devices*)

F: what about environmentally?

Participant 7: I believe that everything is possible, like you see this board, you see where he is seating, so I sure he can see so I think they tried to make something like that, if they tried, if they do something like that I think they can make much difference, and then with the stairs, im sure you've noticed that some of them are painted yellow so we can see that here there's stairs, if they do that with all the stairs around the campus it can help (¹ *Appropriate assisting devices*).

Participant 9: on that one I want the management to know that, you see with students who are totally blind? They use a software called Jooste, I want the management to install them in all computer labs because they are isolating us (¹ *appropriate assisting devices*).

Participant 7: and I would like the management to add to the equipment made for us because now it's just 3 or 4 so if there's someone sitting there does that mean I have to go back? Because I can't see on the small screen (¹ *adequate assisting devices*).

Participant 7: and the issue of printing units, some of us don't have funds and find that I'm printing an A3 and its double the price because last week I had to print like 57 pages and I

had to select which chapters do I think will be in the exam because 57 pages on an A3 its too much so if they tried on that one.

Participant 12: Maybe to cater for us we need the university to like push lecturer to provide slides in class printed with large letters so that we are able to follow I think that would be better (¹ *appropriate assisting devices*)

Participant 17: Yes and maybe do something about some of the projectors so that we can see (¹ *Impaired vision*).

Participant 18: We need better devices for us. Like now they tried like to give us some computers with bigger screens so we can see but if they can work on maybe providing assisting devices at important places in the campus like in the computer labs because even though we are not that many I feel they are not enough. And at least if there were more at the labs we would be able to do like our school work with our classmates in the labs and not be separated (¹ *appropriate assisting devices*).

16. Do you think, your experiences at the University have any impact on you psychologically? If the answer is yes please explain why.

Participant 5: it's just stress even during exams other students are aware what was happening in class and you just waiting for notes and it gives us pressure (¹ *stress*).

Participant 3 some lecturers don't post on blackboard and at least other students copied notes in class I have to stress with a textbook and a textbook has too much information you don't know where to start (¹ *stress*).

Participant 5: I feel like I'm on my own (¹ *depression*)

Participant 2: I think it affects us psychologically, we become emotionally detached like you don't care because people don't care because of their negative attitudes (¹ *depression*).

Participant 1: I experience depression during tests because I have to study something that I didn't get in class and its stressing (¹ *depression*, ² *stress*)

Participant 7: I think it's a 2 minutes thing, once an incident occurs it affects you on that moment. If a person did this to me, it affects me for like 2 minutes and it's okay. You know what I can say ne, is that it indirectly affects us, lets something happens and you are sitting with somebody who does that you'll be like oh and move on with life, but it affects you

indirectly because when you sit with somebody else you start to think what if the same happens, that's how it might affect us (¹ *depression*, ² *stress*)

Participant 8: I think she has a point because if it happens the first time and you move on with life and it happens for the second time it becomes a problem because you ask yourself what's wrong with me.

Participant 9: if something like that happens to me like several times ill just confront you. That's how I am right now. I'll just ask why do you have to leave every time I take the seat and I educate you about my condition

Participant 7: but what if it's done by different people?

Participant 8: it won't always be the same person

Participant 9: I think the issue is with the management, if the awareness, like next year, we will make sure that it's an annual disability week instead of annual disability year, I think that many people will get to learn about us and things change (¹ *adequate awareness about albinism*)

Participant 7: and im suggesting that you guys start to let them know about it now, so that they know that on this is what we saw online because if you tell them like a week before, people will have commitment so if you guys tell them in time, then people will know

Participant 9: and guys, at D block (counselling) they are complaining saying that they don't see us there.

Participant 11: Sometimes I lose confidence when I get hurt or maybe I'm facing challenges in the campus (¹ *depression*, ² *stress*).

Participant 15: It can be depressing hey. Ah that's why sometimes I feel like not going to class (¹ *depression*, ² *stress*).

