

**LIVED SOCIAL AND ACADEMIC EXPERIENCES OF PUPILS WITH ALBINISM:
AT MUMBA SECONDARY SCHOOL IN MONGU DISTRICT ZAMBIA**

BY

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UNZA/ZOU

LUSAKA

2020

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DECLARATION

I, **Agness Ngoma** declare that the dissertation hereby submitted is my own work and it has not previously been submitted for a degree, diploma, or any other qualification at the University of Zambia/ University of Zimbabwe or any other University.

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Signature

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Date

APPROVAL

This dissertation written by **Agness Ngoma** has been approved as a partial fulfilment of the requirements for the award of the Degree of Master of Science in Counselling by the University of Zambia in association with the Zimbabwe Open University.

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Examiner 2	Signature	Date
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Examiner 3	Signature	Date
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DEDICATION

I dedicate this work to my late parents Judith and Isaac Ngoma, blessed memories may their souls continue resting in eternal peace

ACKNOWLEDGEMENT

I would like to thank God almighty for having given me this opportunity, strength, wisdom and knowledge to study at this great institution. I wouldn't have made it without God's intervention to complete my studies. I reservedly give special thanks to my supervisor Dr. J.M. Mandyata who despite his busy schedule, tirelessly guided and supported me throughout as I wrote this dissertation. Sincere gratitude to the coordinator Dr. D. Ndhlovu, Dr. Chikopela, Mrs. Moonga Nzima, Mrs. Ntabo, and Mr. Zyambo for their unwavering support and mentorship and colleagues in Master of Science in Counselling programme for their support in various ways. And to my children Nawa and Joseph Simona your support throughout my two years of study shall forever be appreciated. Thank you for your patience and understanding. May God continue to bless you abundantly.

Special thanks goes to my cousin Tambulukani Banda Mabvuto and my brother Takamikanji Simuchimba for their material support and encouragement. Mr Joshua Kunda, Mr. Kalyata Kanyanga, Mr. Haachizo Patriarchy, for your support. To friends Kapansa Joshua, Mulenga Regina, Biggy Shanzuwa and all my workmates without your support and encouragement I wouldn't have made it. Special thanks goes to Mr. H.B Mkuyamba my colleague and supervisor for your moral support more especially on permissions am greatly humbled. Annety Muwana and Agness Mulenga for encouraging me to enrol as a Masters student I salute you. To God almighty for giving me, humility and patience to depend on Him as run my academic race to its completion.

ABSTRACT

The purpose of the study was to investigate the lived social and academic experiences of pupils with albinism in Mongu district of Zambia. The study was guided by the following objectives: To explore the lived social experiences of pupils with albinism in Mongu District of Zambia? To establish the lived academic experiences of pupils with albinism in Mongu District of Zambia? To determine efforts the study was school making to improve the lived social and academic experiences of pupils with albinism in Mongu District of Zambia? The study made use of a qualitative inquiry grounded on interpretative phenomenological design to explore the lived social and academic experiences of pupils with albinism in Mongu District of Zambia. The sample size comprised: 5 pupils with albinism who were drawn from a selected school in Mongu. Interview guides and focus group discussions guides were used to collect qualitative data. The data was analysed using interpretive phenomenological design in order to transcribe the bulk data into themes and subthemes which were presented descriptively. The results of the study revealed that lived social experiences were evident among pupils with albinism in Mongu. Pupils with albinism were treated differently by their friends because of the colour of their skin. It was believed that their bodies were contagious, sleeping with them cured HIV/AIDS which greatly affected socialization with their peers. Additionally, albino bodies were sold for money and were not treated as human beings but as ghosts. The study also shared that PWA had their skins cracked whenever they were exposed to the sun and their hairs were also used for bringing good luck and improved business which affected ability to interact with others. Furthermore they were discriminated by some teachers and fellow pupils without albinism which made PWA to isolate themselves. Low vision limited their mobility to play around the school which creates low esteem. Skin sensitive also prevented them from playing outside with others due to heat from the sun. As a result they are subjected to being in doors, myths and name calling were revealed to be a major cause of isolation for pupils with albinism in Mongu and were a hindrance to social interaction. Research further revealed that pupils with albinism had lived academic experiences, lacked specialised teachers, materials for braille. Pupils also echoed that they had difficulty writing on the board and teachers were not willing to give them proper notes and explanations in subjects like Mathematics. In addition, the research revealed that they lacked lotion for their sensitive skin and there was no writing with large print on the board, had no computers, and reading glasses. The later affected their emotional, physical and intellectual development. Provision of sunscreen lotion was done by lobbying for funds from the government through the Ministry of Education, donors or Non-Governmental Organizations. However, no much effort was being made to improve the provision of sunscreen lotion because it was expensive. To help pupils with albinism the school to has a deliberate policy to ensure that uniform shirts are long sleeved and skirts are below their knees to avoid direct sunlight. In addition, pupils with albinism are encouraged to do their outdoor activities such as Production Unit and Physical Education and Sports in the morning. During lessons PWA are encouraged to wear hats and sit in front to allow them to see what is written on the board. Further the school embraced learners with albinism by sensitizing teachers who are not specialized in Special Education to accept all pupils regardless

of the colour of the skin, and by having organised worship for all the pupils to promote social interaction and oneness through spiritual guidance.

KEY WORDS: *Albinism; Guidance and counselling; Teacher; social and academic experiences; Secondary education*

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ACRONYMS AND ABBREVIATIONS

PWA -	Pupils with Albinism
HIV -	Human Immune Virus
AIDS –	Acquired Immune Deficiency Syndrome
UNHCR –	United Nations High Commissioner for Refugees
NOAH –	National Organization for Albinism and Hypo pigmentation
UNESCO –	United Nations Educational Scientific and Cultural Organization
UVA -	Ultraviolet

Definitions of Key Terms

Albinism – a person with little or no melanin in the skin, hair or eyes.

Investigate - to carefully examine the facts of a situation or an event.

Lived experiences – understanding of participant’s perception of knowledge.

Low vision – a visual impairment which interferes with a person’s ability to perform everyday activities.

Melanin – a group of natural pigment found in organisms.

Organism – any living thing.

Participants/ Respondents – people who take part in research.

Special Educational Needs – children of school age who have learning difficulties.

Academic- Relating to education and scholarship.

Social-Relating to rank and status in society.

Stigma-a mark of disgrace related with a particular circumstance, quality or person.

CHAPTER ONE:

INTRODUCTION

1.0 Overview

This chapter provides a background of the study, statement of the problem, purpose of the study, objectives and research questions of the study. Then the significance of the study is given followed by the delimitations of the study. The theoretical framework, conceptual framework as well as the operational definition of terms and the chapter summary are given in that order.

1.1 Background

Globally, 1 in 18,000 people have albinism (Aquarum, 1990). In sub-Saharan Africa, it is more common with data from say, Tanzania showing that 1 person in 2 652 has albinism. According to Standing Voice, an international Non- Governmental Organization based in Tanzania, only half of the children with albinism complete primary school and only 10% access secondary school education with very few entering tertiary education or higher education in Africa countries (Baker, 2018).

In Zambia, according to the Central Statistics Office (2016), there are more than 30,000 persons with albinism (actiononalbinism.org). As these children with albinism go to school, they have a lot of challenges. For example, vulnerability to the sun is one of the problems as well as beliefs which are associated with albinism, such as being “ghosts” or depicted in some ways for somehow being half human and have magical properties which bring wealth. Their “difference” supposedly boosts the efficacy of portions or amulets made from their hair, eyes, skin, limbs and other organs. People who are born with albinism are hunted, killed and dismembered or their graves dug up by criminal syndicates in search of their bones (Bradbury, 2018). Another challenge is low vision. Visual impairment of children with albinism means that even if they attend school, their needs are not accommodated in the classroom. Pupils with albinism often experience trauma such as stigmatization, bullying and neglect meaning that their academic and social needs are not fully addressed so as to allow them participate in the learning activities in school. Teachers play an extremely important role in the lives of children with albinism as they can help them to grow, learn and realize their potential. According to (Sharon, 2013). Education is a right to which all human beings are entitled. Since the year 2000, the United Nations has been promoting the millennium

development goals to achieve free universal primary and secondary education for all. Zambia is not left out implying that, children with albinism despite having social and academic challenges equally have a right to education. The right to education is a fundamental human right and every individual irrespective of race, gender, nationality, ethnic, social, origin, religion or political preference, age, or disability are entitled to a free elementary education (Democracy & Education vol 21, No 1).

The Zambian Government's stance, through the Ministry of General Education, on inclusion has been influenced by the Salamanca statement and Framework to which Zambia ascribes (United Nations Educational, Scientific and Cultural Organization, 1994). As a result, the Zambian Government has adopted a policy (Educating Our Future, 1996) that stipulates equal opportunities on discrimination, social justice, protection of basic human rights, and participation of students with disabilities in the main stream activities of school and society. This implies that all human beings have a right to education irrespective of their condition. Myths associated with albinism in Central, Southern and East Africa have a profound influence on lived social and academic experiences of pupils with albinism (Journal of African cultural studies, 2010). Throughout the world, myths function to account for a phenomena which is out of the ordinary or which cannot be explained in other terms, hence fulfilling a fundamental human need to make sense of the world (Lund et al, 1989). The beliefs surrounding albinism in southern Africa are often found to compensate for such a lack of knowledge.

According to United Nations High Commissioner for Refugees, (2020) document on albinism, people with albinism often experience taunting and discrimination. They are accused of being "ghosts" or "witches" or depicted in other ways for somehow being half human. There is also a belief that their bodies have magical properties which bring wealth. Baker et al, (2010) argues that these misconceptions affect family life and interfere with access to education, employment and marriage. Their "difference" supposedly boosts the efficacy of the portions or amulets made from their hair, eyes, skin, limbs and other organs. People who are born with albinism are hunted, killed and dismembered or their graves dug up by criminal syndicates in search of their bones (Bradbury, 2018). The belief common in so many religions is that literal or symbolic cannibalism allows communication with the spirits and deities, and is used for wishing for power and money (Baker, 2010). In Zambia, people with albinism suffer stigma because they are perceived to be less human beings. It is a pity that Zambians have fallen in the belief that people with albinism possess supernatural powers.

As a result of these myths, cases of killing albinos keep on increasing. There are superstitions in some parts of Africa that albino body parts bring wealth, power and sexual conquest and that having sex with a person living with albinism cures HIV/AIDS. As a result, attackers sell albino parts to witchdoctors (Daily-mail.com.zm/lets-p). However, often children with albinism are not seen as worth educating because their social and academic prospects are thought to be limited.

The belief that albinism is a curse from God, or ancestral spirits and unfinished creatures have a profound effect on social and academic lived experiences of pupils with albinism. Baker et al, 2010 argues that these misconceptions affect family life and interfere with access to education, employment and marriage. Additionally there are beliefs among the communities that people with albinism are ghosts and that this is associated with great misfortune (Bradbury, 2018). However, often children with albinism are not seen as worth educating because their social and academic prospects are thought to be limited. The lack of information by local people on albinism surprisingly affects teachers and attitudes to these pupils due to reliance on myths and misinformation (Journal of African Cultural Studies, 2010). It must be noted that there are in fact no cognitive and academic learning disabilities associated with albinism except that albinism is a rare genetic condition that limits the body's production of the pigment melanin in the skin, hair and eyes (Baker, 2018).

Children with albinism face a number of challenges in school which, amongst them, is low vision. The visual impairment of children with albinism means that although they attend school, their needs are not accommodated in their classroom (Hess, 2010). The practical problems associated with albinism in southern Africa are numerous. People with albinism are vulnerable to the sun burns, long-term skin damage and have increased risk of developing skin cancer (Aquaron, 1990: Luande, Henschke and Muhammed, 1985: Kromberg et al, 1989). The reduced visual acuity associated with the condition makes daily life difficult. Nevertheless, with appropriate health information, eye care facilities and provision of skin protection creams, albinos can manage effectively (Lund, et al, 1997). Low cost strategies such as wearing protective clothing, avoiding the sun during the middle of the day when ultra violet levels are at peak could be helpful. However, in much of Africa people with albinism remain much excluded from education and social security. In Zambia, cases of attacks have been reported, according to the Albino Foundation of Zambia. Persons with albinism also have safety concerns stemming from social prejudice driven by harmful traditional beliefs.

Teachers can remove the physical barriers to learning, for example, by rearranging the school schedule so that outdoor activities take place in the morning or late afternoon to protect the albinos from the unnecessary sun exposure. Additionally, educators can also contribute to fostering an understanding of children with albinism and end name calling as well as the use of common yet disrespectful labels and dispel misconceptions about albinism. Encouraging them to achieve through stressing to them that, they have the same potential as others without albinism. The effective integration of children with albinism into the mainstream schools has the potential to shape the attitudes for the better (Baker, 2018). It is against this background that this study sought to explore the lived social and academic experiences of pupils with albinism in selected secondary schools in Mongu District of Zambia.

1.2 Statement of the problem

The educational path of children with disabilities is strewn with logistical, social and economic pitfalls (UNESCO, 2015). That means that they often face a compromised school experience if they are enrolled. Most parents have fear that children with albinism face a lot of challenges such as discriminatory admission policies, lack of reasonable accommodation and shortage of sufficiently trained man power. Other challenges being the Lack of inclusive curricular, lack of Individualised Educational Programs, discriminatory fees, and expenses that further marginalise children with albinism from poor families (United Nations Children’s Fund, 2012). Although this information is available in literature, the question still remains as to what are the lived social and academic experiences of pupils with albinism pursuing secondary education? It is on this basis that, the study had to explore the lived social and academic experiences of pupils with albinism in selected secondary schools in Mongu district of Zambia.

1.3 Purpose of the study

The purpose of the study is to explore the lived social and academic experiences of pupils with albinism in selected secondary schools in Mongu district of Zambia.

1.4 Objectives of the study

- (i) To explore the lived social experiences of pupils with albinism in Mongu District of Zambia.
- (ii) To establish the lived academic experiences of pupils with albinism in Mongu District of

Zambia.

- (iii) To determine efforts the study schools were making to improve the lived social and academic experiences of pupils with albinism in Mongu District of Zambia.

1.5 Research questions

- (i) What are the lived social experiences of pupils with albinism in Mongu district of Zambia?
- (ii) How are the lived academic experiences of pupils with albinism in Mongu District of Zambia?
- (iii) What efforts were the study schools making to improve the lived social and academic experiences of pupils with albinism in Mongu District of Zambia.?

1.6 Significance

The significance of the study of lived social and academic experiences of pupils with albinism is to help pupils with albinism deplore different copying strategies in their social lives. To help parents understand the importance of education to pupils with albinism. To assist policy makers as sponsors of educational programs to be equipped with knowledge to address the social and educational challenges encountered by pupils with albinism in various institutions of learning. To help administrators and teachers on how they can adjust the curriculum to meet the social and academic challenges of pupils with albinism.

1.7 Delimitations

The study was confined to one school which had pupils with albinism in Mongu District of Western Province of Zambia. It was believed that teachers and pupils living with albinism in the school has sufficient experiences to contribute positively to the present study. Generally Mongu is known to have quite a good number of albinos than any other district in the entire country. Therefore pupils with albinism were a target and sampled in the study.

1.8 Limitations

According to Price and Murnan (2004), limitations are influences that the researcher cannot control. These are short comings, conditions or influences that cannot be controlled by the

researcher that place restrictions on the methodology and conclusion. The study focussed on pupils living with albinism excluding pupils without albinism. Data was collected from one school. There was refusal of some pupils to participate in the study due to stigma, fear, isolation and name calling. However all the participants used their free will to take part in the study without being forced. The number of participants in the study was small 5 participants only. The findings of this study therefore might not be generalised to other Secondary Schools in the District.

1.9 Theoretical framework

In this study, the researcher used the stigma theory by Goffman (1963) to examine and understand the experiences of learners with albinism. The theory and analytical frame work for theorizing experiences of learners with albinism, looking at discrimination and marginalization created by categorizing by the so called normal in society.

Goffman defines a stigmatized person as one that poses an attribution that is deeply discrediting. He further mentions three types of stigma. The first one being ‘abnormalities of the body’ that includes different types of physical deformities and conditions such as blindness, low vision and deafness. The other one is the blemishes of individual character perceived as weak will, unnatural passions, dishonesty. These being inferred from a known reward of mental disorder, unemployment, and radical political behaviour. The third one is the tribal stigma of race, nation and religion. Following these three, there is substantial evidence regarding the psychological impact of low vision on persons with albinism (Hess, 2010). People who have sight problems are most likely to experience lack of social support than the general population. Similar findings are reported for learners with albinism in schools. Children with visual impairment due to albinism are reported to be at risk of social exclusion and of being stigmatized due to impairment (Hess, 2010). Goffman (1963) maintains that the discrimination social exclusion and disapproval results in a spoiled identity of the stigmatized. This study therefore will help fill the gap on lived social and academic experiences of pupils with albinism.

1.10 Conceptual framework

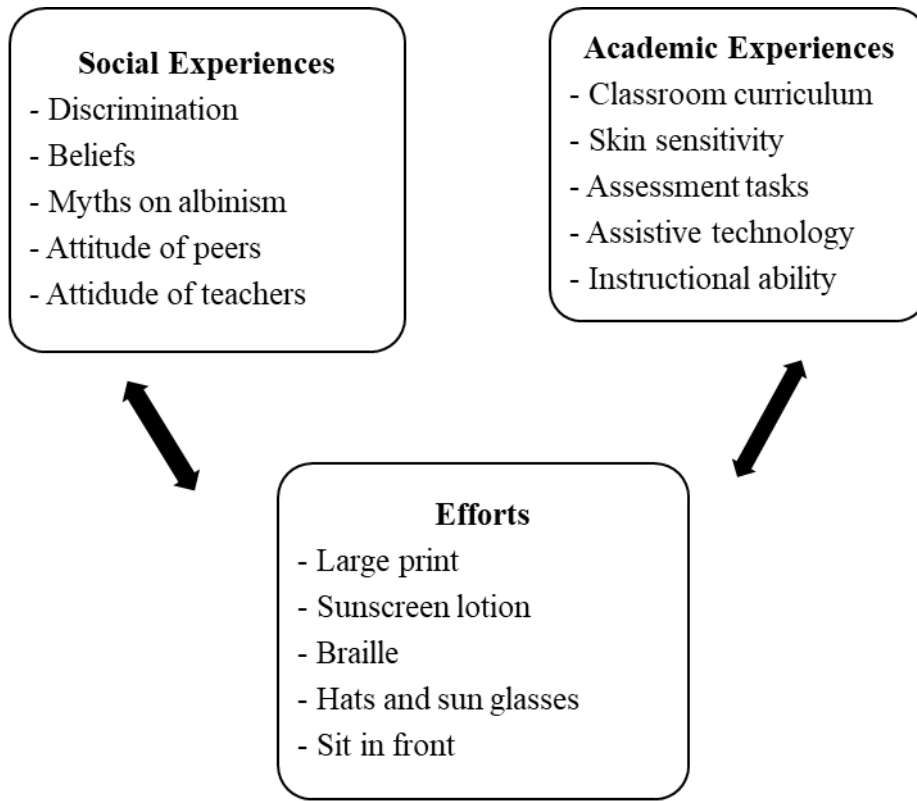
Lived social and academic experiences affect pupils with albinism as they enrol in school they face a compromised school experience. This is as a result of the following factors namely: discrimination, myths about albinism, attitude of peers and attitude of teachers.

Discriminatory language has just as much, power to exclude as other forms of marginalization (Gottlie, 2001: Sigail, 2010). It therefore represents an effective lens through which to analyse the social position and consideration of people with albinism. Pupils with albinism have academic experiences which include lack of inclusive curriculum, skin sensitivity, difficult in assessment tasks and shortage of sufficiently trained teachers in special education.

The Ministry Education came up with the policy of Inclusive Education so that, every child can be integrated into the main stream despite their condition. Nevertheless, not every school has managed to implement this policy in order to accommodate pupils with disabilities such as albinism. These pupils still struggle as they enrol in school, to be accepted socially by their fellow pupils and teachers.

Efforts should be made to adjust the curriculum by ensuring that they are allowed to sit in front as they write and read from the board, provided with braille materials, reading glasses, large print and sun screen lotion, and avoid direct sun. It is so disheartening to see pupils with albinism struggle to be accepted socially and academically as they attend school.

Figure 1: Lived social and Academic Experiences of Pupils with Albinism in Secondary education



1. 11 Chapter Summary

The section is a summary the content of chapter one which has looked at the overview, The background of the study and the statement of the problem as well as the purpose of the study including the objectives, research questions, significance of the study, and conceptual framework. Further, it has highlighted the delimitations, theoretical framework conceptual framework before citing operational definitions and indeed a summary. The study is to investigate the lived social and academic experiences of pupils with albinism in Mongu District. The next chapter deals with review of related literature deemed relevant to the study based on its objectives which included to; explore the lived social experiences of pupils with albinism, establish the lived academic experiences of pupils with albinism and determine efforts the study school was making to improve the lived social and academic experiences of pupils in Mongu District.

CHAPTER TWO:

LITERATURE REVIEW

2.0 Overview

The previous chapter highlighted on the introduction to the study which gave the background to the study, the problem statement, purpose, objectives, research questions, significance, theoretical framework, delimitation, limitation and operational definition of terms. This chapter reviews some important literature on lived social and academic experiences of pupils with albinism in the education system. The literature is based on the research objectives which included to: explore the lived social experiences of pupils with albinism, establish the lived academic experiences of pupils with albinism, and determine efforts the study school was making to improve the lived social and academic experiences of pupil's with albinism in Mongu District of Western Province of Zambia. The chapter begins with a paragraph what is literature review.

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

2.1 Challenges associated with pupils with albinism

Discrimination against learners with albinism

Discrimination against pupils with albinism is still evident. Socially, they are not seen as similar as others. Instead, they are seen as 'different' from those that are part of the African population. People with albinism are expected to exclude themselves from the educational system, employment opportunities, transport system and housing conditions (Baker et al, 2010). Despite this misinformation lived social and academic experiences of pupils with albinism in Mongu District of western province are not known

In Zambia, discrimination against people with albinism is an age-old problem. Children are said to be the worst culprits because, naturally they tend to be hostile to people who look different from them. A school child with albinism will not have it easy in interacting with classmates without being scorned because of weird beliefs that people have about albinism. It takes a brave child to prevail over unfriendly comments and rejection by peers and stay in school until one successfully completes one's education (daily-mail .co.zm /albino).

According to Albinism Foundation of Zambia Chairperson Duncan Lalusha, parents are scared of sending albino children to school because of, first of all, their security which is not guaranteed and, secondly, the stigma and discrimination creates a hostile environment for the young. “I would like to believe that the sense of insecurity by parents comes from baseless beliefs that people have, about the body parts of people with albinism. It is for this reason that in sub-Saharan, senseless murders of albinos for body parts are common in countries like Tanzania and Malawi” (Zambia Daily Mail 2015).

Lund (1997), in her study in Zimbabwe, concluded that Pupils with albinism can be successfully evolved in the mainstream if teachers could cater for their poor sight and sensitive skin. Further, Kromberg, (2018) mentions that visual impairment of children with albinism means that although they attend school, their needs are not accommodated. They will also often have experienced serious trauma such as stigmatization, bullying or neglect. Findings in a study by Monyemore (2007) in Gauteng province in South Africa concurs with Gaigher’s (2002) findings that the majority of PWA were of the opinion that the problems they experienced at school were more of social than educational nature. Lack of social interaction perpetuates the situation of affected persons because it means that, they cannot access essential services such as health and educational facilities to meet their physical and developmental needs.

Dart, et al (2010) in their double study found that PWA were performing poorly across all subjects due to the fact that their social and academics needs were not addressed more especially low vision and also the scorching sun. Not only were they performing poorly at high schools but evidently it had been like that even from early ages. In a study by Brethem and Ingested (2006), one of the participants narrated that one of the challenges she faced as she moved to secondary school was the teachers’ bad attitudes and unwillingness to support her such that she decided to leave school and got married.

However, in Zambia, according to an action research study done by Miles (2011), efforts were being made by the government to promote the welfare of PWA in the country by prohibiting racial discrimination against the albinos as well as offences that cause bodily harm through the constitution and the penal code of Zambia. Supporting the publication of a handbook called “Living with Albinism in Zambia”. This was in an effort to teach young people with albinism about health care, sun damage and the difference between them and

their family and peers (Zambia Daily Mail, 2015. Lived social and academic experiences of pupils with albinism in Mongu District are not known.

2.2 Beliefs and Myths about Albinism.

Myths around albinism affect learners with albinism in general. According to Baker and colleagues (2018), myths are formed out of the need for human beings to make sense of the unexpected and unanticipated events. Some harm them psychologically and others physically. Some of the myths are life threatening to PWA. These include the myth that the sacrifice of a person with albinism calms the many gods of the mountains when the volcano erupt (Roura et al 2010, Machoko, 2013).

In addition, the study by Deborah et al (2010), in Tanzania revealed that, miners use the bones of persons with albinism as amulets or bury them where they are drilling for Gold and that fishermen weave the hair of persons with albinism into nets to improve their catches. Myths such as albinism is a contagious condition that makes the so-called normal children not to eat with children with albinism or even sit close with them in class. Other challenges include the belief that children with albinism are mentally retarded and those that play with them will be retarded (Lund, 2010). In Zambia there are many negative beliefs about albinism such as homes of people with albinism are cursed because of the wrong done by the family, or that people with albinism don't die, they just disappear which is a common belief in Southern Africa (daily-mail.co.zm/super).

Some people think traditional concoctions made from body parts of persons with albinism can make one rich or that unprotected sex with a woman with albinism will cure HIV/AIDS. People with albinism have been attacked, murdered, abducted, survived brutal attacks in isolated incidences (Lusaka times, 2018). In an action research study by Miles (2011), one teacher expressed fears of having an albino in class because she feared sores on his hands and according to the teacher's belief, when one saw an albino one had to spit saliva on his or her chest. Fear driven by superstitious beliefs have negative impact, though lived social and academic experiences pupils with albinism are still not known. Pupils with albinism have low esteem, stress and isolation which leads to dropping out of school, myths make the pupils with albinism uncomfortable, superstitions and lack of understanding that surround albinism and visual differences can lead to stigmatization, lack of acceptance, perception of difference and social interaction (UNHCR, 2020).

Television and radio play a big role in perpetuating myths about albinism. This is because people with albinism play characters that portray ghostly supernatural powers (Franklin, Lund, & Taylor, 2018). However, such portrayal only increases the negative perception and further adds more value to myths concerning albinism. If albinos were to be portrayed in a positive manner, eventually acceptance, understanding and change of negative perception can be achieved faster than its current rate, however lived social and academic experiences of pupils with albinism in Mongu District are not known.

2.3 Attitude of peers towards Albinism

An attitude is defined as a psychological tendency to view a particular object or behaviour with a degree of favour or disfavour. Attitudes are understood to be formed through the process of individual subjective evaluation (Albarracin et al, 2005). Selepe (2007) in her study of teenagers with albinism notes that one of the challenges experienced in schools is name calling. National Organization for Albinism and Hypopigmentation (2005), further highlights that name calling, teasing, curiosity and being insensitive to learners with albinism is lack of knowledge, the desire to learn and inability to pose questions constructively. In Canada, Wan (2003) mentions that learners with albinism were called ‘whitey’ ‘powder’ ‘ghost’ and ‘casper.

In Malawi, Breathen and Ingestad (2006) found that learners with albinism were called ‘muzungu’ meaning white man, ‘zigoma’ name of famous gospel singer with albinism in South Africa. Ngindi (2005), remembers names like ‘inkawu yasendlini’ meaning house monkey, sphiwo – gift, ilawu – light skinned person. In Zambia however, children with albinism are called ‘bamwabi’ in Bemba, one of the local languages. As a result, they are ridiculed, bullied and at times beaten by fellow pupils. This is because they are treated as misfits or outcasts and at times avoided by their peers who refuse to sit or eat with them NOAH, (2010).

2.4 Attitudes of teachers towards Albinism

Teacher support to learners with albinism makes a huge contribution to scholastic achievement. According to Dart et al, (2010), learners with albinism perform poorly across a range of subjects. This does not start later in their school lives but evidently so even in primary school. This could be due to the fact that there are very few teachers trained in the area of special education to meet the needs of children with albinism and lack of understanding from their teaching staff at the schools.

The study will fill the gap on lived social and academic experiences of PWA in selected schools of Mongu of western province. In Zambia, pupils with albinism are discriminated socially and academically because of the myths, stigma, bullying, name calling associated with the condition. Academically, pupils with albinism face a lot of challenges in class especially when it comes to writing on the board, sitting arrangement, prevention against the sun as well as being unable to have access to braille and braille materials (daily – zm.com/super). Socially, pupils with albinism are isolated because of the following problems: vision, skin problems, stereotype which affect their learning. It is because of these challenges that pupils with albinism are academically and socially affected. Unsympathetic teachers often order these poor sighted learners to sit down if they happen to stand up in order to move closer to the black board (albino foundation.org). Sitting position for learners with albinism could pose poor learning attainment if the learner is seated in a position where it is easy for the light that is entering the classroom directly. Books have normal font which is a challenge to learners with albinism poses as reading and writing problems (NOAH 2010).

Teachers should change their attitude towards pupils with albinism by creating an ideal environment for learning, as well as discouraging bullying and facilitating acceptance, allowing them to get closer enough to the book by ensuring that each pupil with albinism has his /her own copy of text book and teacher's notes so that they can read them at a closer proximity when needed. Teacher's notes should be clear and in large print. Extra time should also be considered and allow pupils with albinism to complete their tasks and additional time to read questions, (Dart et al, 2014).

Teacher's attitude towards pupils with albinism can help them understand that each child is a unique individual and where possible, adjustments need to be tailored accordingly they can benefit from low vision devices like magnifiers but must be appropriate to the needs of individuals and recommendation from a vision doctor (albinism-in-africa.com). Attitudes may prevent learners with albinism from accessing education if they are secluded Chitiyo and Chitiyo, (2001).

2.5 School Curriculum and Albinism

Dart et al (2010), says that the curriculum comes with content to be taught, methods and procedures to be followed in teaching and assessment. Lived social and academic experiences affect PWA in the area of classroom curriculum. The curriculum in the classroom has to be adjusted in order to suit lived social and academic experiences of pupils with albinism by

ensuring that teachers remove the physical barriers that create social and academic challenges to pupils with albinism Florian (2014).

This can be simple changes such as seating a child so that they aren't in direct sunlight, allowing them to wear a hat indoors to help protect their eyes, protecting them from bullies. Ensuring that they move closer to the board and making tasks and materials more accessible (the conversation.com). Teachers can also contribute to fostering an understanding of pupils with albinism. Dart, et al, (2014) in their double study concluded that teachers can end name calling, the use of common yet irrespective labels that dispel misconception about albinism. They can encourage young people with albinism to achieve by stressing that they have the same potential as others. The effective integrating of pupils with albinism into the main stream schools also has the potential to shape their attitudes for the better. Pupils with albinism should avoid the middle of the day when the damaging Ultra Violet rays are strongest and arrange outdoor activities early or late in the day.

The classroom curriculum should be adjusted to suit their needs by protecting them from unnecessary exposure from the sun. For example, giving them indoor tasks as well as encouraging indoor leisure activities (albinism-in-africa.com). Furthermore, Tomlinson, (1996) in his studies on albinism states that, it is the education system that calls for the school to modify the learning environment to suit the needs of all learners. Including those with disabilities such as albinism that, they are able to learn in a regular school together with peers. Studies by Baker, (2010) acknowledges that; these simple and affordable measures do not require any expenses. However, they require teachers' knowledge, positive attitude and learning expectations towards students with albinism.

2.8 Skin sensitivity Among Albinos and Effect on School work

According to Farage (2019) Sensitive skin has been described as an unpleasant sensory responses to stimuli that should not provoke such sensations. Objectively measurable signs of irritation are not always present in individuals with sensitive skin, however, subjective sensory effects such as itching, burning, stinging, tightness, and dry are consistently present. Gaigher, Makuya and Lund (2002) are of the opinion that learners with albinism are isolated from activities that stimulate cognitive and perceptual motor development because they cannot take part in outdoor activities and other extra mural activities due to their poor eye sight and highly sensitive skin. As such, some of these learners with albinism feel like they are being segregated (Franklin et al, 2018).

2.8 Assessment tasks and Albinism

Assessment tasks are activities learners will undertake to confirm whether or not the outcome has in fact been achieved Biggs & Tangs (2007). Some tasks can be highly difficult for learners with albinism and find it difficult to keep up with the pace of other learners. The progression report ends up reflecting the incompetency of the learner instead of knowledge of the subject content Coe (2013).

2.9 Efforts Made by Learning Institutions

Teachers can remove physical barriers to the lived social and academic experiences of PWA by making for example simple, adjustment to accommodate individual learning needs of each pupil. These can be changes such as seating a child with low vision in a place that is not direct with the sun, allowing them to wear a hat indoors to protect their eyes, long trousers skirt or a long sleeved shirt and allowing them to move close to the board and making tasks and materials more accessible as well as the use of large print. Giving them their own book to read rather than sharing and allowing them to sit in front in the middle of the board. Furthermore, use of colour, shapes or patterns to help identify and find objects, (Ashley, 1992).

In addition, asking people to speak so that a pupil with albinism can recognize their voice and follow lessons in class. As well as do their tasks like reading early, when they are still fresh rather than late in the day. There is need to advise pupils to use sun cream lotion for those who can afford although this is expensive and also asking for well-wishers and government to assist because it might not be freely available Zambia Daily mail (2015).

Teachers can also help children manage the fact that their skin is sensitive to the sun, they can arrange the school schedules so that outdoor activities take place in the morning or late afternoons, encourage PWA to use sunglasses to protect the children with albinism from unnecessary sun exposure. This can also include the use of magnifiers that enable pupils with albinism to hold in their hands to make letters and numbers larger with the help of donors Franklin et al (2018).

Dart et al, (2014) in his double studies on albinism asserts that, teachers can also contribute to fostering an understanding of children with albinism. They can help to stop name calling, beliefs in certain myths, and the use of common yet disrespected labels and dispel misconception about albinism. This can be in a form of fostering the use of the guidance and

counselling teacher who can have sessions with all children in a school for them to understand albinism

2.10 The identified research gaps

The aforementioned reviewed literature had a lot to offer to the current study in that no secondary school in Zambia can provide education to pupils with albinism without addressing the following lived social and academic experiences such as segregation and discrimination by others pupils and some teachers which makes them to isolate themselves. Treating them differently because of the colour of the skin, and their bodies being contagious, sleeping with them to cure Hiv/Aids and selling albino bodies for money, treating them as ghosts, and lack lotion made their skin to crack whenever they were exposed to the sun. Pupils with albinism had their hairs used to bring good luck and improved business. Poor sight limited their mobility around the school and created low esteem. Their sensitive skin prevented them from playing with pupils without albinism outside due to heat from the sun and are subjected to being in doors. Myths and name calling are a major cause of isolation which secondary schools must address allow pupils with albinism attain access to secondary education,

Although many studies world over have clearly shown that pupils with albinism have lived social and academic experiences as they attain secondary education no clear documentation of a comprehensible literature was found by the researcher on lived social and academic experiences of pupils with albinism. There is lack of specialised teachers, materials for braille difficulty seeing and writing on the board, no proper explanations in subjects like Mathematics, by teachers. No large print, lack of computers and reading glasses. However to help pupils with albinism, secondary schools made a deliberate policy to ensure that uniform skirts are below the knees and shirts are long sleeved to avoid direct sunlight. Doing outdoor activities such as Production Unit and Sports in the morning. Encouraged wearing hats and sitting in front to allow them to see what is written on the board. The secondary school organises worship for all pupils to promote social interaction and oneness through spiritual guidance and counselling.

2. 11 chapter Summary

This chapter discussed the literature review. It began by reviewing studies done on challenges associated with pupils with albinism such as discrimination against learners with albinism, myths about albinism, attitude of peers, attitude of teachers, classroom curriculum and

albinism, skin sensitivity, assessment tasks, efforts, thereby creating knowledge gap that the current study intends to address. The next chapter discusses the methodology employed in the study.

CHAPTER THREE:

METHODOLOGY

3.1 Overview

The previous chapter gave a review of some important literature on challenges associated with albinism such as discrimination, myths, attitude of peers, attitude of teachers, classroom curriculum, and skin sensitivity, assessment tasks, and efforts made. The current chapter presents the methodology used in the study which includes: the research design, target population, sample size, sample strategy, research instruments, secondary data collection, and primary data collection, data analysis, ethical consideration and chapter summary.

3.2 Research Design

According to Cresswell (2014), a research design is a framework of methods and techniques chosen by a researcher to combine various components of research in a reasonably logical manner so that the research problem is efficiently handled. Kombo and Tromp (2006) further defines a research design as a glue like structure that holds all elements together in a research project. Orodho (2003) defines it as a scheme, outline or plan that is used to generate answers to the research problem. The study used an interpretive phenomenological research design with the intention of conducting a “direct exploration”, analysis, and interpretation of a particular phenomenon emphasizing on the richness, breadth and depth investigation as interpreted by participants in detail Creswell, (2009). With the phenomenological research design the researcher, therefore was able to tap into the lived social and academic experiences of pupils with albinism regarding their access to education. The design appropriately guided the generation of interpreted information on the lived social and academic experiences of pupils with albinism. Therefore, the study was purely qualitative in nature and was done only in one selected school in Mongu of Western Province of Zambia.

3.3 Target population

Population is defined as a group of individuals and objects from which samples are taken for the measurement Kasonde Ng’andu, (2013). The population for this study consisted of pupils with albinism in Mongu District of Zambia.

3.4 Sample size

A sample according to Sharma, Srivastava and Shenoy (1983) is the group of people who take part in the investigation and have similar characteristics. The sample population of lived social and academic experiences of pupils with albinism, School in Mongu District of Zambia comprised five (5) pupils. Namely pupil N, pupil L, pupil S, pupil M, pupil X. The reason for restricting the sample to five was ultimately a matter of judgement and experience on the part of the researcher and at that time only examination classes were operating due to corona virus outbreak. The researchers need to evaluate the quality of information collected in light of the uses to which it is applied. Nevertheless, Sandeloski, (1995) states that, in determining the sample size in qualitative research, there is no specific formula. Therefore the researcher used her own personal judgement to determine the sample size in this study.

3.5 Sample procedure

Alvin (2016) states that, when using purposive sampling, the sample is approached having prior purpose in mind. However sampling techniques are classified into non- probability and probability, the study applied non-probability sampling techniques with the intention of selecting individual participants for the sample that does not give all the individuals in the population equal chances of being selected. Purposive sampling was used which involves purposely handpicking individuals from a population based on the researcher's knowledge and judgement Msabila and Nalaila, (2013). Nevertheless the study used typical sampling among other types of purposive sampling because the study involved pupils with albinism who were potentially familiar with the lived social and academic experiences of pupil with albinism in attaining secondary education. Orodho and Kombo,(2002),states that the power of purposive sampling lies in selecting information rich in cases for in-depth analysis related to the central issue being studied.

3.6 Research instruments

These are measurement tools designed to obtain data on a topic of interest from research subjects (Price & Murnan, 2004). In view of this, the researcher, used interview guides and focus group discussion guides to collect data on the lived social and academic experiences of

pupils with albinism in Mongu District were interview guides and focus group discussion and to ensure the trustworthiness of the data collected triangulation technique was used.

3.6.1 Interview Guides (IG)

On interview guides, questions were asked orally Kombo and Tromp, (2006). One to one interviews were used to collect data from pupils on the basis of qualitative inquiry which usually produces in-depth data. It is from this basis that the researcher was able to understand the lived social and academic experiences of pupils with albinism in Mongu District. Kombo and Tromp, (2006) acknowledges that, interview guides are based on the use of an interview guide which is a list of questions or topics to be covered by the interviewer, interview guides are flexible because they contain both open and closed ended questions, they are significant to the study because they gather in-depth information which gives the researcher a complete and detailed understanding from questions. Therefore, using interview guides enabled the study to get first-hand information from pupils with albinism on the lived social and academic experiences.

3.6.2 Focus Group Discussion Guide (FGDG)

Focus Group Discussion Guide (FGDG) is designed to obtain information on participants' experiences, beliefs and perceptions on a defined area of interest Kombo and Tromp, (2006). Focus group discussions was used as an instrument to collect data from learners with albinism. The rationale for choosing (FGDG) pupils was to help them feel comfortable to express their opinions in the presence of their peers who in this regard helped to create a natural environment for them. As a result, the researcher decided to categorise groups as the only way to elicit information as they socialise and interact among themselves in a simplistic manner. The purpose of focus group discussion is to obtain in - depth information on concepts and ideas of the group due to its open endedness that enables it to collect subjective view from participants.

3.7 Data Collection Procedure

Data collection is the gathering of specific information aimed at proving and refuting some facts on how a researcher collects data and with what instruments Kasonde Ng'andu, (2013). This process of gathering and measuring information on targeted variables in an established system, enables one to answer relevant questions and evaluate outcomes. Therefore, in trying to follow the data collection procedure, clearance and introductory letters were sought from

the University of Zambia ethical committee and school of education, department of science in counselling to allow the researcher to go for data collection, written permissions was sought from (DEBS). At school level, verbal permission was obtained from the head teachers of the selected school to use their facilities before proceeding with data collection. After the researcher was given permission to go ahead with data collection by the head teacher, she later travelled and went to administer interview guides among learners which lasted for 50 minutes and focus group discussions which lasted for 45 minutes because the learners had termly assessment implying that, the researcher had to wait for learners to be organised together in one classroom. However, before collecting data from participants, the purpose of the study was thoroughly explained to pupils and assurance was given that data to be collected was purely for academic purposes. During data collection, a voice recorder was used to record the conversations to capture the opinions and views of the participants in order to help the researcher with data analysis. Furthermore, the researcher was accompanied by two interpreters who were conversant with the local language in the area to help pupils who had difficulties to express themselves in English and where the researcher could not get what was said in the local language English as an official language was used.

3.7.1 Secondary data collection.

Secondary data collection on lived social and academic experiences of pupils with albinism in Mongu District was obtained through public documents, journals, past researches and internet as used in the literature review.

3.7.2 Primary data collection.

In this study on lived social and academic experiences of pupils with albinism in Mongu District, primary data was collected from the field using interview guides and focus group discussion.

3.8 Data analysis

White (2005), describes data analysis as the process of systematically applying statistical and logical techniques to describe and illustrate, condense and recap and evaluate data. On the other hand, Durrheim (1999) states that data analysis is aimed at converting information into answers. However, appropriate methods of data analysis are determined by the data type, variables of interest and number of cases. Therefore the data collected from the field through interview guides and focus group discussion guides on the lived social and academic

experiences of pupils with albinism was qualitatively analysed manually through coding and categorizing of themes that emerged from the study. Data from both interview and focus group discussions and literature review was matched in order to link corresponding ideas for easy analysis

3.9 Ethical Consideration

Ethics are norms or standards for conduct that distinguish between right and wrong. They help to determine the difference between acceptable and unacceptable behaviours (merriam-webster.com). Cohen, et al (2000) acknowledged that ethical issues are matters which are highly sensitive to the right of others. In this regard, ethical issues are were upheld in the study. To start with, a clearance letter was obtained from Directorate of Postgraduate Studies and the researcher sought consent from the University of Zambia Ethical Committee, District Education Board Secretary (DEBS), and head teacher from a selected school. Therefore the researcher ensured that the study was clearly explained and made known to the participants and that there was no emoluments or incentives attached to the study thus the research was purely academic. The researcher did not force participants to be part of the study, consent was sought from respondents to be involved in the research. Only those that were willing to participate in the study were engaged. Those who declined were respected too. In addition the researcher assured participants that data to be covered would be kept confidential and only used for research purposes, the researcher also assured the participants that names and personal details would not be mentioned or published and names of schools and participants were represented by certain codes such as letters of the alphabet this assured anonymity. However the researcher had to take full responsibility for the study and unforeseen consequences it could attract. All these mentioned activities had to be done in order to ensure that rights of participants were respected and dignity as human beings was safe guarded.

3.10 Chapter Summary

This chapter discussed the methodology employed in this study. Under methodology the following items were captured: the research design, target population and sample population including the sample strategy, research instruments, data collection, secondary and primary data, and data analysis. Having presented the aforementioned, the next chapter presents the findings of the study from sampled secondary school in Mongu District.

CHAPTER FOUR:

PRESENTATION OF THE FINDINGS

4.0 overview

The previous chapter outlined the methodology employed by the researcher to come up with data by means of the stated research instruments. This chapter presents the findings of the study as provided by the participants. The findings are presented according to the study questions. The study questions are as follows:

4.1 Research objectives

- (i) What are the lived social experiences of pupils with albinism at the study school in Mongu District of Zambia?
- (ii) How are the lived academic experiences of pupils with albinism at the study school In Mongu District of Zambia?
- (iii) What efforts was the study school making to improve the lived social and academic Experiences of pupils with albinism in Mongu District of Zambia?

4.2 Participants Profile

In this section, the study describes the participants who participated in the study which carried out an investigation on lived social and academic experiences of pupil with albinism in Mongu District. Participants in the study were given letters of the alphabet to avoid exposing their real names as follows: Pupil X, Pupil L, Pupil N, Pupil M, and Pupil S. The information is aimed at enabling readers have a picture of the participants whose voices have led to the findings being presented in the study. Participants who participated in the study share common experiences which were familiar with the respondents in Mongu.

4.3 Lived social experiences of pupils with albinism at the study school in Mongu District of Zambia

The researcher took time to interact with the participants through interviews and focus group discussions so as to appreciate their personal experiences on lived social experiences of pupils with albinism. The presentation of the first question was, what are the lived social experience of pupils with albinism in Mongu

4.3.1 Views of Pupils with albinism on lived Social experiences

Pupils with albinism have lived social experiences which are inter-related. These lived experiences include the following: segregation and isolation by other pupils without albinism and some teachers, myths, low vision and skin sensitive make pupils with albinism to isolate themselves because pupils without albinism fail to freely interact with them as they attend school.

In support of the assertion above pupil N stated that:

“We isolate ourselves and friends treat us differently, our body parts are used for prosperity. We cure HIV/AIDS when you sleep with us and our bodies are contagious, we don’t die but disappear.”

While pupil L added that:

“Our bodies are sold for money, we don’t die they disappear, we are ghosts and sleeping with us cures HIV/AIDS.”

On the contrary according to pupil N she further stated that:

”We are able to interact with others especially when comes to having an organised worship by the school which promotes social interaction.”

Low vision is another social lived experience which affects pupils with albinism because it limits their mobility around the school. For example PWA fail to interact with others and explore the environment which affects their ability play with others and this creates low self-esteem. In support of the above stated assertion pupil X mentioned that:

”We have poor sight”

Skin sensitivity is another social lived experience which affects pupils with albinism in a sense that when it is too hot they cannot go out and play with others due to heat from the sun as a result they subjected to being indoors in order to protect their skin from direct sunlight further too much heat causes skin cancer. Being in doors isolates them from interacting with other pupils and exploring the environment. In support to the above mentioned assertion Pupil N stated that:

“Our skin cracks when we work in the sun.”

Name calling is another social lived experience which affects pupils with albinism. For example, they are given names such as ghosts, mentally retarded, white person, and a curse from god and sometimes they are treated differently from others which further discriminates them from other pupils. This creates stigma and stereotypes toward pupils with albinism. In support of the assertion above Pupil M also lamented that:

“We are affected by myths, poor sight and sensitive skin, our bodies are sold for money, also we don’t die we just disappear. Sleeping with us cures HIV/AIDS, we are ghosts and if you eat with us you can get albinism.”

While pupil L further added that:

“Our bodies are sold for money, we don’t die they disappear, we are ghosts and sleeping with Albinos cures HIV/AIDS.”

In addition pupil S also mentioned that:

“Friends sometimes don’t treat us equal, they isolate us, and call us names like whites, ghosts and albinos. When we are killed our bodies are used in rituals.”

Furthermore, pupil X said that:

” Our body parts are removed and used in rituals, our hairs are used for good luck, we don’t die but disappear and we are ghosts.”

In addition according to the findings, Pupil M mentioned that:

“Our body parts are used as rituals for prosperity, we just disappear, we don’t die and eating with us cause’s albinism, we are ghosts. We do not interact with others freely at this school. We are segregated, we are discriminated by fellow pupils and teachers.”

Nevertheless, Pupil L further lamented that:

“We are used to cure HIV/AIDS if one sleeps with us and they also get our hairs and use it for rituals, we are called white people.”

However, to the contrary of the assertion above pupil X stated that:

“We participate in all school activities we are not segregated, we are given attention and that sacrifice of us pleases the gods. We are contagious and mentally retarded, our hairs improves business.”

In addition to the above assertion pupil M stated that:

“We interact with friends we have an organised worship at school and sacrifice of us brings prosperity. Sleeping with us cures HIV/AIDS and using our hair makes fishermen improve their catch and we are ghosts. Other people say that we are cursed and we are ghosts, white people and mentally retarded.”

4.4 Lived academic experiences of pupils with albinism at the study school in Mongu

District of Zambia?

Pupils were further asked on what are the lived academic experiences of pupils with albinism at the study school. The study found that pupils with albinism have lived academic experiences during interview and focus group discussions.

4.4.1 Views of Pupils with albinism on lived academic experiences

Research findings on lived academic experiences of pupils with albinism prove that pupils with albinism have lived academic experiences which include lack of specialized teachers, relevant materials such as braille and computers. They equally talked about bad attitude of teachers and peers towards them.

In support with the assertion above pupil S stated that:

“Lack of specialised teachers, we don't have materials to use”

Furthermore, pupil X stated that:

“We have difficulty writing on the board, teachers do not respond well to us. They don't give proper notes and explanations especially in mathematics and we lack lotion.”

In addition pupil L agreed that:

“We don’t see on the board, other pupils don’t sit next to us, attitude of teachers. Teachers do not allow us to ask questions.”

However, pupil M lamented that:

“Attitude of teachers, pupils don’t sit near us, we don’t see on the board.”

Furthermore, pupil A also stated that:

“The teachers are not specialised, there is no writing with large print on the board and no computers.”

Pupil M acknowledged that:

“We Lack of materials to use like braille papers as well as glasses.”

4.5 Efforts being made by the study school to improve the lived social and academic

Experiences of pupils with albinism in Mongu District

Of Zambia

Pupils with albinism were further asked on what efforts the study school was making to improve the lived social and academic experiences of pupils with albinism. Pupils reported that efforts are made to improve the lived social and academic lived experiences of pupils with albinism at the selected School in Mongu District.

4.5.1 Views of pupils with albinism on Efforts made by the institution

Pupils with albinism on efforts being made by the institution to improve the lived social and academic experiences of pupils with albinism reported that the school provides sun screen lotion, teachers make pupils sit in front when writing on the board and use large print, do production unit and sports in the morning, pupils with albinism wear long sleeved shirts and long skirts for girls as uniform.

Pupil S on the contrary starts that:

“No efforts have been made, in the provision of sun cream lotion to protect us against the sun.”

Pupil X stated that:

“They have not done anything to improve or help us, sometimes they provide sun cream to protect us against the sun, and do outdoor activities in the morning, wear a hat with a wide brim indoor.”

Pupil L stated that: *“we should be doing our work early in the morning before it becomes hot due to our skin sensitivity. Sit in front, wear a hat, use of sun cream lotion and use of colour shapes and patterns to identify objects.”*

On the contrary Pupil N also asserted that:

“Teachers ensure that we sit in front and write on the board with large print, provide sun cream lotion. We wear long sleeved shirts and long skirts to avoid direct sun.”

Furthermore Pupil M claimed that:

“We do our work early in the morning before it is hot. Wearing a hat in class, we use colour shapes and patterns to identify objects and sun cream lotion.”

4.6 Summary

The presentations of findings of the study are direct responses from participants and observations of the researcher. It is clear that lived social and academic experiences exist among pupils with albinism. Pupils with albinism are discriminated, lack social interaction, isolated, stigmatized, given various labels. Myths attached to albinisms, create attitudes among peers and teachers because of beliefs about it. Low vision, lack of adjusted school curriculum, small print, are evident among pupils with albinism. Skin sensitivity robs them the opportunity to interact and engage with other pupils.

CHAPTER FIVE:

DISCUSSION OF THE FINDINGS

5.0 Overview

The previous chapter presented the findings of the study. The present chapter discusses the findings of the research and further relates the findings to other studies noted in chapter two. Discussion of the findings is presented with reference to research objectives of the study as follows: to explore the lived social experiences of pupils with albinism in Mongu District of Zambia, to establish the lived academic experiences of pupils with albinism in Mongu District and to determine efforts the study school was making to improve the lived social and academic experiences of pupils with albinism in Mongu District. The chapter will end with a summary.

5.1 Lived social experiences of pupils with albinism

The research revealed that there were lived social experiences among pupils with albinism in Mongu District. Pupils with albinism were isolated and treated differently by their friends. Furthermore the research revealed that there were myths about albinism being contagious and that sleeping with them cured HIV and AIDS. In support of the above findings Baker and Colleagues, (2018) states that myths compensate for lack of knowledge, discrimination, beliefs, superstitions and misconception.

On exploring the lived social experiences of pupils with albinism it was revealed that albino bodies were sold for money and that they were not treated as human beings but as ghosts. In addition, the research further revealed that pupils with albinism developed cracked skin whenever they were exposed to the sun and their hair was being used in rituals to bring wealth and good luck.

The research highlighted that pupils with albinism in Mongu District faced isolation due to low vision and skin sensitivity because of their inability to explore the environment, social interaction and manipulate objects. Pupils with albinism were discriminated by fellow pupils and some teachers which made them to isolate themselves thereby missing out on interaction with other pupils without albinism and the environment. This was in line with the research findings supported by Journal of Education and Practice, (2018). Furthermore, pupils with

albinism deserve the best out of the education system because they have the right to education like any other child without albinism.

Research findings revealed that low vision was another lived social experience of pupils with albinism, which limited their mobility around the school and affected their ability to play with other pupils who had no albinism. The inability to explore the environment fully creates low self-esteem and makes pupils with albinism to lose confidence in themselves and make them fail to interact with pupils without albinism freely.

The study revealed that skin sensitivity was another lived social experience of pupils with albinism. When it is hot, they cannot go out to participate in sports competitions and other outdoor activities like Production Unit due to heat from the sun. Their skin, which is sensitive, if not well taken care of, could deteriorate into cancer of the skin. As a result they are subjected to being indoors which isolates them from interaction with others and exploring the environment (Zambia Daily Mail, 2015).

Further, it was established that discrimination was another contributing factor to lived social experiences of pupils with albinism. Pupils with albinism were discriminated by fellow pupils and some teachers because of myths which surround them. Myths are created by society and they work against pupils with albinism in a negative way which results in name calling. The findings are in support with Baker, (2018), who states that myths are formed out the need for human beings to makes sense of the unexpected. In addition Lund et al, (1989) acknowledges that throughout the world, myths function to account for a phenomena which is out of the ordinary or which cannot be explained in other terms. Hence fulfilling a fundamental human need to make sense of the world.

This is the situation with Albinos, society lacks understanding of their condition because they lack knowledge on albinism, as a result it has created so many myths about them, which brings a lot of fear, insecurity and threatens their lives as they attend school.

Discrimination against pupils with albinism

Research has established that there was discrimination against pupils with albinism as one of the lived social experiences. Despite discrimination being an age old problem, children are said to be the worst culprits because naturally they tend to be hostile to people who look different from them. It takes a brave child to prevail over unfriendly comments and rejection by peers and stay in school (Zambia daily mail 2015).

Myths about albinism

The study revealed that another lived social experience of pupils with albinism were myths which resulted into name calling. Myths are life threatening to pupils with albinism which affect them physically and psychologically. Pupils with albinism in Mongu District were treated differently by other pupils without albinism because of myths that surround their existence such as sleeping with an albino being a cure for HIV/AIDS, their body parts being sold for money to bring prosperity and not being treated as human beings but as ghosts who never died but just disappeared and albinism was contagious. It was revealed that myths made pupils with albinism to isolate themselves from other pupils without albinism because in class they are ever in front to see and write which further creates discrimination Bradley, (2018).

5.1.3 Attitude of peers

Attitude of peers is another lived social experience of pupils with albinism. Research established that pupils without albinism are not able to mix freely because of the beliefs which society has attached to the condition. Name calling, teasing, curiosity and being insensitive to pupils with albinism was lack of knowledge. Pupil with albinism are able to interact and play with other pupils but low vision robs them the opportunity to explore the environment.

Name calling contributed to lived social experiences, names such as” muzungu” which means white man. As a result they are ridiculed, bullied and at times beaten by fellow pupils. Research also revealed that Pupils with albinism isolated themselves from other pupils. The above findings were in line with NOAH, (2010) who acknowledged that pupils with albinism are treated as misfits and at times avoided by peers who refuse to play or eat with them.

Skin sensitivity

Skin sensitivity is another lived social experience which affects pupils with albinism in Mongu District. Research established that pupils with albinism were not allowed to play with other pupils without albinism when it was hot. This was because of their sensitive skin which reacts to heat from the sun. Research revealed that they had blisters and sores a sign that, they lacked sunscreen lotion to protect them from excessive heat. It was revealed that too much heat caused pupils with albinism to develop skin cancer, having them indoors prevented them from such a problem. However keeping PWA indoors disadvantaged them from exploring the

environment and socializing with friends. The research findings are positively linked to those of Gaigher, Makuya and Lund,(2002) which states that learners with albinism are isolated from activities that stimulate cognitive and perceptual motor development because they cannot take part in outdoor activities or extra mural activities due to poor sight and highly sensitive skin.

5.2 Lived academic experiences of pupils with albinism

The study revealed that pupils with albinism had lived academic experiences. According to research findings, two pupils with albinism confirmed that lived academic experiences were evident in Mongu. This was supported by pupil X and pupil N who attested that; they lacked materials for braille and attitude of teachers and peers affected their academic performance. In addition, Pupil S echoed that they lacked specialized teachers trained in special education. Research findings, revealed further that pupils with albinism had difficulties writing on the board due to poor sight which contributed to poor performance in class as they failed to see clearly. The study, revealed that pupils with albinism lacked proper notes and explanations specifically in mathematics. And lacked sun screen lotion to protect them from the sun as the cream was too expensive for them coming from vulnerable homes.

Research revealed further that pupils with albinism lacked computers and large print which was a requirement for them as it enabled them to see on the board. These pupils acknowledged further that they lacked braille as well as reading glasses. In support of the research findings, it was revealed that pupils with albinism were unable to take part in sports activities and Inter-school Competitions with pupils without albinism and other outdoor activities such as Production Unit due to heat from the sun. Research findings, revealed that lived academic experiences created a barrier as it impacted on their emotional, physical and intellectual development as supported by Lund& Gareth, (2014) who revealed that effective integration of pupils with albinism in the mainstream schools has the potential to shape their attitude for the better. If society fails to remove the barriers to education the potential of pupils with albinism shall be lost. Getting them into school and accepting them socially is only a first step that can enhance their academic achievement as echoed by Baker, (2018).

Attitude of teachers

Teachers' attitude towards pupils with albinism makes a huge contribution to scholastic achievement. Research on establishing lived academic experiences of pupils with albinism in

Mongu District revealed that PWA were not given proper notes and explanations in mathematics and also lacked specialized teachers who were trained, in special education to understand their academic challenges. Pupils with albinism in Mongu lacked access to braille and braille materials, furthermore research revealed that they were unable to see on the board because of poor vision as acknowledged by Hess (2010) who states that, people who have sight problems are most likely to experience, lack of social support than the general population. Implying that, pupils with visual impairment due to albinism are reported to be at risk of social exclusion and of being stigmatised due to impairment.

Teachers wrote in small print which advantaged pupils without albinism. They also acknowledged that when copying notes they had to move in front so that they can see what was written on the board. In addition, teachers were not very willing to write in large print. Computers were also not available which contributed to their poor performance. According to (albino foundation.org) unsympathetic teachers often order these poor sighted learners to sit down if they happened to stand up in order to be closer to the black board. Books used in a classroom normally have normal font which is not suitable for pupils with albinism thereby posing reading and writing challenges which could cause poor learning attainment if they are not able to see clearly.

Curriculum and albinism

Curriculum comes with content to be taught, methods and procedures to be followed in teaching and assessment. Research revealed, that pupils with albinism in Mongu District had difficulties seeing on the board due to lack of large print. It was further revealed that the school made simple changes to accommodate pupils with albinism by making them sit in front when an exercise is given, doing outdoor activities such as Production Unit and Physical Education and Sports in the morning and afternoon instead of midday when there is direct sunlight

Allowing them to wear hats and uniforms that are long sleeved as well as long skirts for girls. Simple changes in the curriculum facilitates effective integration of pupils with albinism in the main stream and shapes their attitude for the better Baker, (2010).

Assessment tasks and Albinism

Assessments are activities learners undertake to confirm whether or not the outcome has been achieved .The study on establishing the lived academic experiences of pupils with albinism

revealed that, they had challenges with assessments because local examinations were written in small print and pupils with albinism in Mongu were unable to clearly see due to poor vision which results in them having poor grades. There is no provision for large print and pupils with albinism are made to sit in front most of the time. Furthermore, they lacked learning materials like braille and computers which affects their academic achievement. Some tasks are very difficult to achieve. The study confirmed that pupils with albinism in Mongu had difficulties to understand concepts in mathematics because there were no proper explanations given for them to understand. The study is in agreement with Coe, (2013) who stated that the progression report ends up reflecting the incompetency of learners instead of knowledge of the subject content.

5.3 Efforts the study school was making to improve the lived social and academic experiences of pupils with albinism

Two pupils out of five attested that no much effort was being made to improve the provision of sun screen lotion to protect them against the heat from the sun which hindered them from participating in outdoor activities such as Production Unit and Inter-School Competitions. However, three out of five pupils with albinism revealed that, the school made efforts to improve lived social and academic experiences by organizing worship sessions to allow pupils with albinism interact with those without albinism in order to promote social interaction. Furthermore, other efforts made by the school included ensuring pupils with albinism sat in front so that they were able to see on the board.

Wearing of long sleeved shirts and skirts for girls to avoid direct sun as well as providing sunscreen lotion by sourcing for funds from government through the Ministry of Education and Non-Governmental Organizations (NGOs) were some of the efforts which the study school was making to improve the lived social and academic experiences of pupils with albinism in Mongu District of Zambia. Sunscreen lotion was essential in the lives of pupils with albinism because it protected them from long skin damage which increased the risk of developing cancer. The findings of the study are supported by Aquaron, (1990) who revealed that pupils with albinism are vulnerable to sun, in support Lund, et al (1997) further states, that reduced visual acuity associated with albinism makes daily life difficult however, with appropriate health information, eye care facilities and provision of sun screen lotions albinos can manage the lived social and academic experiences.

It was further revealed that the school was making efforts by ensuring that pupils with albinism did their Production Unit and other outdoor activities like Physical Education and Sports in the morning before it became hot as well as sensitizing teachers and other pupils without albinism to embrace every child regardless of the colour of the skin. Additionally the school encourages teachers to write in large print. However, one pupil with albinism revealed that local examinations were prepared in small print despite teachers knowing their lived academic experiences which needed to be improved.

5. 4 Summary

The chapter presented the findings of the study and the researcher's position was in line with the findings based on data collected during the study. It was clear that pupils with albinism had lived social and academic experiences such as isolation, discrimination, low vision, skin sensitivity, lacked braille and specialized teachers as well as sun cream lotion, failed to see on the board due to small print. However efforts were being made by the school to ensure that pupils and teachers were sensitized, and provided with lotion, braille, doing of outdoor activities in the morning, used large print and integrating them in the mainstream school. The literature that was revealed was in conformity to the findings stated above. Nevertheless, lived social and academic experiences can still be avoided if pupils with albinism are not segregated from playing with those without albinism by simply making minor changes which affect them while they are in and outside the classroom. However, it was observed that they are denied the chance to play with other pupils which deprives them from developing, social skills necessary for their adult chores.

Academically not every child with albinism was doing very fine in assessment. It is the duty of the school administrators and teachers including the community and other Stakeholders in Mongu District, to educate others on albinism as a condition which cannot affect anyone. It is also vital to note that, every child is able to learn as long as one is given an enabling environment. Teachers should show that willingness to teach them in order to transform their lives academically, so that they are able to excel in their career choices. In addition they also desire to play and interact with anybody without pointing fingers at them, shunning, or giving them nick names which affect their self-esteem.

CHAPTER SIX:

CONCLUSIONS AND RECOMMENDATION

6.1 Overview

The previous chapter presented the discussions of the finding of the study. The current chapter discusses conclusions and recommendations of the study.

6.2 Conclusions

Based on the findings of the study, it was established that lived social and academic experiences exist in Mongu District of Zambia. Pupils with albinism should not be discriminated, but given the chance to learn by adjusting the school curriculum to suit their social and academic needs. Teachers as providers of education in the country have a responsibility to provide quality education to every child regardless of their status or physical condition. Pupils with albinism deserve the right to attain secondary education just like any child, what is needed was understanding their lived social and academic experiences by providing an enabling environment which is learner friendly where pupils with albinism can equally enjoy playing with other pupils without albinism while attending lessons with less difficulty. Social interaction and play are important to every human being because they enhance mental and cognitive development which makes education attainable and provides quality secondary education as well as quality social life.

6.1 Recommendations

These recommendations were based on the research findings as follows:

1. The school should to ensure that pupils with albinism do their Production Unit and other outdoor activities in the morning when it is not very hot so that they can participate.
2. The school through the Ministry of Education should sensitize teachers on the use of large print to help pupils with albinism read and write on the board.
3. The school through the Ministry of Education should encourage the use of braille and computers though there are very few teachers trained in special education.

4. The school should encourage pupils with albinism to participate Inter-School Competitions and worship sessions to offer spiritual guidance and encourage change of attitude towards pupils with albinism.

5. Government through the Ministry of Education should take a centre stage in providing sunscreen lotion and learning materials for pupils with albinism in all learning institutions

6.3 Future Research

The focus of the study was to explore the lived social and academic experiences of pupils with albinism in Mongu District. The study revealed enough information to identify lived social and academic experiences of pupils with albinism which affect their daily life. A number of gaps were noticed during the study and therefore some issues for future research may include:

1. No research has been conducted in Mongu District on exploring the lived social and academic experiences. Since this research was limited to only one school instead of selected secondary schools of Mongu District due to Covid -19 restrictions there is need to carry out a country wide research in order to explore the lived social and academic experiences of pupils with albinism in other parts of the country.

2. Formulating educational policies which will address the social and academic challenges encountered by pupils with albinism in various learning institutions in the country.

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APPENDICES

APPENDIX (I)

Interview schedule for learners with albinism

Dear respondent,

I am a post graduate student from Zimbabwe Open University trying to investigate the lived school experiences of children with albinism. You have been randomly selected to help answer the questionnaire on the topic. Be assured that the information given is for education purposes only and will be treated highly confidential.

Instructions:

Tick [] or write briefly in the spaces provided.

SECTION A: Background information.

1. Gender of respondents

Male []

Female []

2. Grade []

Age []

Section B

3. Lived social and academic experiences affect pupils with albinism, mention the problems that you face in this school?

(i)

(ii)

(iii)

(iv)

(v)

4. Do you think pupils with albinism are discriminated by some teachers at this school?

Disagree []

Agree []

5. Peers have very bad attitude towards pupils with albinism at your school

Agree []

Disagree []

6. Is the classroom curriculum suitable to meet your academic needs?

Agree []

Disagree []

7. The performance of children with albinism in class is not good

Agree []

Disagree []

8. The attitude of teachers towards children with albinism is not very good

Disagree []

Agree []

9. Myths affect pupils with albinism. Mention some of the myths you experience in this School?

- (i)
- (ii)
- (iii)
- (iv)
- (v)

10. What efforts are being made by the selected schools on lived social and academic Experiences of pupils with albinism?

- (i)
- (ii)
- (iii)
- (iv)
- (v)

Thank you for your participation

APPENDIX (2)

Interview schedule for Pupils

Dear respondent,

I am a post graduate student from Zimbabwe Open University trying to investigate the lived school experiences of children with albinism. You have been randomly selected to help answer the questionnaire on the topic. Be assured that the information given is for education purposes only and will be treated highly confidential.

Section: A Background information

Tick [] or the correct answer briefly

Age of Respondents

Gender [] Age []

Section: B

1. Do think children with albinism have lived social and academic experiences at this school/

Agree [] Disagree []

2. What are some of the lived social and academic experiences of pupils with albinism?

- (i)
- (ii)
- (iii)
- (iv)
- (v)

3. What are some of the challenges associated with albinism at this school?

- (i)
- (ii)
- (iii)

(iv)

(v)

4. Do you think children with albinism are discriminated by teacher in this school?

Agree [] Disagree []

5. The interaction between children with albinism and so called normal in school class is good.

Agree [] Disagree []

6. The performance of pupils with albinism in class is very good.

Agree [] Disagree []

7. Do you think African tradition and myths affect children with albinism, mention some of the myths that you face in school?

Disagree [] Agree []

8. Teachers attitude towards pupils with albinism is not bad.

Disagree [] Agree []

9. Which myths are associated to pupils with albinism?

(i)

(ii)

(iii)

(iv)

(v)

10. What has the school done to minimize the lived social and academic of children with

Albinism at this school?

(i)

- (ii)
- (iii)
- (iv)
- (v)

Thank you for your participation