

**CARING FOR A CHILD WITH ALBINISM: A PASTORAL  
CHALLENGE**

**By**

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## DECLARATION

I, **Maria Shadibo Diale (Rev.)** hereby declare that this dissertation, which I submit for the Degree of Master of Arts in PRACTICAL THEOLOGY at the University of Pretoria, is the product of my own work and has not been previously submitted by me or anyone else at this or any other University. All sources, which I have used, have been acknowledged by means of comprehensive list of references.

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## ABSTRACT.

The absence of proper, effective human developmental plan in communities has detrimental effects on the rearing and caring of children with different skin pigmentation. Children living with Albinism are not spared from this effect as they are classified with impairments of visual, hearing, or physical, which restrict them from full and equal participation in society. Their existence as individual are questioned based on their skin pigmentation and nothing else. The higher the impact makes churches and communities to be challenged and they end up losing their moral ground. In other countries, the same children have lost their lives, and it is not documented on how did the church or community of faith console, heal or exercise compassion.

There is perceived inadequacy in the area of pastoral care and support services to families who are in danger of misguided beliefs due to a child born with Albinism. The care offered to such family's shows adequacy from the side of the church and pastoral care practitioners.

This research raises several questions that will guide this project.

That are the children living with Albinism given enough care and respect. Are pastors aware of the circumstances they are experiencing on the individual? How can this problem be corrected by the church? These are few of the questions that drove into having this research. The aim of this research is to first investigate these perceptions, misguided beliefs and sub cultural myths that surrounds their births. This will establish the link between the communities, pastoral care practitioners and families that have children living with Albinism. In addition, will give clarity on the factors contributing to their inhuman treatment.

There are no best international practices on how to communities can deal with Albinism. Churches and religious institutions were against such humiliation; however, the whole exercise ended there ended there, without any documented information on the level of after care to those affected. A great deal of work done has been on the concept such as children with other disabilities, (special needs) and cerebral palsy this is according to (Chimhenga and Musarurwa: 2011). The data of this study was collected from different individuals with interview and was analysed descriptively. A semi-structured interview was conducted with the help of a professional Social Worker and self-constructed questionnaire was used as a qualitative data collection. The guideline in the findings provided the conclusion of this study. That People living with Albinism needs to be cared for. Based on the above objectives, the model created is address their challenges and help the church community and pastors to engage.

## **ABBREVIATIONS, KEYWORDS, DEFINITIONS GLOSSARY AND ACRONYMS**

**Albinism:** (noun) is a congenital lack of normal pigmentation in the skin and hair of a person or animal or in the coloration of a plant.

**Albino:** a person or animal whose skin and hair lack pigmentation and whose irises are pink because of a hereditary condition. Sometime it can be a plant that lacks normal coloration because of a hereditary condition.

**Pastoral care:** refers to the overall ministry of the pastor. This ministry includes preaching, teaching, discipline, nurturing people, caring in times of need.

**Pastoral counselling:** this is a more specialized aspect of pastoral care. It involves helping individuals, families or groups as they cope with the pressures and crises of life by means of deliberation(s).

**P.L.W.A.** An abbreviation for; People Living with Albinism

**N.O.A.H:** An abbreviation of National Organization for Albinism and Hypo pigmentation

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Annexure B. Questionnaire (one list of Questions)

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## CHAPTER ONE.

### **Caring for a child with Albinism: A Pastoral Challenge.**

#### **1.1. INTRODUCTION TO RESEARCH**

A child living with Albinism experiences unjustified and malicious attention and trauma due to external appearance. They are exposed to what Nthongoa (2017) describes as "a journey of their everyday challenges, the love they encounter and the terrible danger they face- just by their very existence..." They are always exposed to an unsubstantiated level of emotional abuse, due to unusual sub-cultures and old myths that are not proven. As they are not conscious of their pigmentation, as they are still young and at developmental stages, in certain quarters of the communities in Africa and beyond they have met their sudden death.

The non-exposure to relevant anthropological knowledge and human sciences as far as human bodily processes and framework are concerned has led to children living with Albinism being ostracized, maimed, or even murdered in a form of trying to wipe them out of the planet earth. To some because of misguided beliefs they have been cruelly harmed as it was thought that they are a curse or punishment from the ancestral worldview. However, ignorance cannot just be the only reason for emotional, physical, and other related scary acts meted out on these people of different skin pigmentation to those who are darker and beyond.

The children living with Albinism have not been afforded an opportunity as far as Nthongoa is concerned to live a life as individuals and as human beings (2017), too often; they are called by offensive and belittling names and live as underdogs. They have to go through agonizing and hurtful life because of skin pigmentation, which is not of their own making. It is in the light of the above challenges, hurt, humiliation, and death in some instances that the study became a prerogative for the researcher, as the researcher could no longer sit and idle or contribute to misguided beliefs and inhuman handling of other human beings.

#### **1.2. Background**

From a school Principal who told me that I have to take the children to attend a special school, to a member of a church who told me that, "she was asked if her womb was white by someone she

knows in the church". I realized that people always have something judgmental to say about people with albinism.

All judgment is set on assumptions, and all these assumptions represent a much bigger problem than one-person enfolded observation. However, that problem will not be resolved by correcting them with anger. The common prejudices about people with albinism are shocking, but considering an unfair and inaccurate portrayal in the church and society, they are hardly surprising

The central argument in this study is the child's nurturing and caring of children with Albinism, which is not visible to the parents, children, and the community surrounding that child. The observation of the researcher is given severity by the story related to by a congregant whom the researcher journeyed with in her pastoral life.

*Within the Platinum belt in the Villages of North West where the researcher served as a minister, there is a story of Gobakwang.*

*Gobakwang (not real name) excitedly waited for, to be born into the family, no one had the slightest expectation that the new member of the "bundle of joy" would come with albinism.*

*The child was born to parents who did not know how and what to do in rearing the child, with such a condition. They did not comprehend whether is this disability, a deficiency of some sort in its body, an ailment that will be healed over time or a bad omen from the ancestors or punishment from God.*

*The mother was not hospitalized during labour; she was at home and assisted by the home-based midwifery to deliver the child. It did not cross the minds of the midwifery to choke the child as it is alleged that through oral tradition when they see that is a child with albinism, they are to choke it so that it does not live, and they will say " **ngwana o tlile a lapile**" (loosely translated that the child came already tired). Though this cannot be verified as it is things that are held as "**phithhela, tse di fitlhegileng kgotsa tse difitlhilweng tsa pelegi**" childbirth secrets, unknown to men and other instances to the giving birth woman due to labour pains. This is something that requires more research as it is not the study for now.*

*Gobakwang family was overwhelmed as they did not know what to do, and how to handle the child, as the situation unfolds. Painfully so, the skin pigmentation and the eyes were never experienced in the family history. Question after question was asked on what is happening and*

*why to them? The unfolding situation and streamline of questions and comments caused tension in the family, which resulted in the child being named in Setswana, “Gobakwang”, simply implying: “what are you all arguing about?”*

*The birth of Gobakwang brought a lot of private, public talks, and gossips within the community of Sarone. In the family of nine siblings, he was the only one born with that condition and was mocked to be having supernatural intelligence and special powers than others. The majority were light-skinned tones with a few who were darker in skin tone. Misguided beliefs, unproven myths started to mushroom all over the area that he will not die, but in the far distant future, Gobakwang will disappear to an unknown place. The child was believed to be a lucky charm of some sort to the family. This myth leads to strangers to see him as a blessing economically.*

*The rearing mother was subjected to humiliating and inhumane questions and lived a life of explaining even things she did not understand on the pigmentation of the child. How is she going to rear him, and is she not afraid of the disappearance of the child?*

*The human developmental, that is, physical, mental, psychological, and spiritual growth of Gobakwang got difficult and problematic by the family in the sense that they lacked the knowledge of his condition. They were not conversant with how to care for him, which, made him vulnerable and exposed to external misguided beliefs of their time.*

*For several unknown reasons Gobakwang’s family did not allow him to commence schooling with children of his age group. Their argument put forward was that it is in his interest to be emotionally protected from being mistreated. As a result, he was isolated from his peer group.*

*He started schooling at the age of 10 years, instead of 7 years as the family was compelled not to expose him to the severe sun heat due to his skin texture. All got further complex as the child grew under the watch of the grandmother, who kept him indoors at all the time, arguing that he does not need to be exposed to the sun, as it was said that his skin is very sensitive and fragile. The grandmother's protective strategy from the severe sunrays was to cover the child's skin with cow dung, use a large brim hat to cover his face, and to protect his eyes from too much sunlight. The grandmother stirred up candle wax to smear him on the body parts, which were aimed at preventing sunburns.*

*Gobakwang never got a chance to be a child, nor play with other children, in other words, he was not allowed to be in the street for boy’s games.*

*Though the family especially the grandmother wanted to protect him from the ultra-violet rays of the sun, on the other hand, other children through the influence of their parents to a greater extent did not want to play with him, because they did not know how to deal with him.*

*Associating with him because of skin pigmentation, in the worldview of the other young children was not healthy, as they thought that he was injured and they would ask their parents why Gobakwang's parents are not taking him to the hospital as he is injured.*

*Very fragile and sensitive as the skin was, the researcher picked up that the family never consulted with dermatologists, pharmaceuticals, and medical practitioners to get sound advice on handling bodily care of Gobakwang. Instead, the grandmother continued with candle wax, which could not moisturize the sensitive and fragile skin. He began to suffer from sunburns around the neck, ears, and hands. His lips started to crack due to excessive dryness, bled, and developed diseased infections, which needed serious medical attention.*

*The innocent young child developed dark gangrenous spots on his skin and under the armpits. On consultation at a medical facility, they were informed that the diagnoses are showing a harmful disease in a form of cancer.*

*Serious health matters cut short Gobakwang educational journey as he had to drop from primary school at grade 5 due to an unknown and unfamiliar disease called **nystagmus**, a medical condition defined as an involuntary eye movement resulting in poor eyesight (NOAH 2009:39). The problem resulted in the family, the community, and the church not knowing how to care for him.*

*Gobakwang's life got complicated from all sides, grew up kept indoors, dropped at lower grades out of school, and had to face the harsh realities of seeking employment as a growing young man. All of this and other complicated health-related matters resulted in Gobakwang's life being complicated by unusualness that even devoured his spirituality, the reservoir of deep-down conscience. In the whole tale of Gobakwang is never mentioned that he complained about the people's misguided beliefs, the perceptions towards him, and the myths surrounding people of his skin texture. As a young person, Gobakwang never saw himself different from other young people, however, the community, the family, and pastoral practitioners around him did not offer him such support or idea.*

In as much as parents are not to be exposed to the psychoanalysis of how do the genes, hormones, and chromosomes operate during reproduction to result in a life that is short of certain levels of skin pigmentation, it devastates them too.

The sub-cultures, traditions, and misguided beliefs begin to haunt the parents as soon as they see that the pigmentation of their child is different from theirs and others. The burden and load of social objections rise above the joy of receiving and accepting that a child has been born into the family in particular and into society in general. With them, too derogatory statements will be floated around and in certain instances, there will be the gossip that "*one a ratisiwa lekgowa faa imile*" (loosely translated that "she had a crush on a white man whilst pregnant"). Though this is indeed ignorance beyond comprehension, it goes with unproven and unconfirmed misguided beliefs and tales. Trauma embraces family members more especially the mother of the child.

For the researcher, this is not a common paradigm; however, lifelong challenge impact as it registers its effects on the family, especially the childbearing and child-rearing mother. The scenario captured by the researcher advances the effects of caring for a child with Albinism, painfully so as the first account had elements of death and destruction.

The other implication was of trying to deconstruct the social myth that has been in place as old as culture that said people with Albinism do not die but disappears.

The unfolding story, the one narrated by the researcher on Gobakwang is within South African and is a condemnation to the pastoral world as there is no mention of pastoral care and support services. Chapter two will further expand on these matters after unpacking the terms around "*albino*" and "*albinism*". That would be to show how they are treated from being human beings to nothingness. It would be laying a foundation to Chapter four that will be interrogating the pastoral approach based on the missiological concept of the image of God, the "*Imago Dei*".

That when and how did people with Albinism lose their image of God?

### 1.3. Problem Statement

Two different incidents prevailed in two different environments. I did not know how to handle both incidents.

This raised questions in the researcher's mind.

- a. Are people living with Albinism given care and respect?

- b. How can their dignity and respect be restored?
- c. Are pastors equipped in caring and journeying with them?
- d. How can families be empowered to care for them?

#### **1.4. Research Aim**

The aim to:

1. Investigate the misguided beliefs and sub-cultural myths around the birth, nurturing, and caring of children with Albinism.
2. To further consider what the pastoral care practitioners can offer to support them and their families.

##### **1.4.1. Research Objectives**

To help create a link between communities, pastoral care practitioners, and families have children with Albinism, and provide a holistic approach to handling the pressure they endure in their lives

#### **1.5 Research Gap**

There is no literature on caring for people with Albinism in the pastoral care field. The research will be one of a kind in this field in an African context. It focuses on the Pastoral care perspective and will mean to wrestle with the issues of the cruelty they endure from an African pastoral care perspective. A great deal of research has been undertaken on the issue related to the killings.

The research will contribute to the field of Practical Theology and in particular pastoral care by providing a unique approach to the no mechanism in pastoral care spaces.

Caroline Bradbury -Jones and Patricia Lund, on their research, mentioned this, “Although Albinism includes a group of an inherited condition that resulted in reduced melanin production. It has been documented across the World, with high frequency in Sub-Saharan Africa. There is very little published research about the lives of people with Albinism, but available evidence shows that the myths abound regarding their condition. They conducted a qualitative study on the 8-district region of Uganda between 2015 and 2017. Their findings showed that there is still much to be done to address the pervasive and potentially harmful beliefs and misconceptions about the people living with Albinism. (2018; 10)



From what they have, argued none of them writes about caring for children living with Albinism in the South African context.

According to Sullivan, Tanzania, Kenya also had a challenge with people mutilating persons with Albinism for various reasons including the enhancement of business with their body parts (2013:7).

Therefore, churches and religious institutions were against such humiliation and dreadful acts towards other human beings. However, no research was conducted on Pastoral care.

The whole exercise ended just there, without any information on the fundamental level of aftercare to those traumatized documented so as it can assist the future pastoral practitioners. A great deal of work has been on concepts such as children with disabilities, "special needs" and cerebral palsy by Chimhenga and Musarurwa (2011). There is nothing from the institutions of higher learning in South Africa on the care of children with Albinism from a theological perspective in general and pastoral care in particular.

The gap has shown to be a decisive essence for pastoral care practitioners as much as those that are counselors of Christian background in general. Fields such as psychology and sociology have tied together with their research on human behavioural patterns and trends towards persons of Albinism. They can explain and express when a person of that stature is under distress and depression due to external social pressures that challenge his or her status based on skin pigmentation. Their counselling revolves around human behavioural trends outside the spiritual being, which is a constituent that pastoral care practitioners have overlooked.

### **1.6. Significance of the Study**

A conversation with a member of the church about Gobakwang created the thought of this study. As a Practical Theology student about to do research, I realized a passive practice in community churches. Although I had not come across a direct incident of a discriminatory incident to people living with Albinism in a church, I asked myself some questions, which are recorded, on the problem statement. The research will not only demonstrate that gaining an understanding of the church relates to people with Albinism and their care, it is also necessary for clergy and the church community. It will also impart cultural relevance to living with these people. In that case,

this research will not only be an intellectual contribution, but also a necessary practical tool for the church and clergy.

The study cannot leave all those who care for children living with albinism and provide to families that are rearing children with Albinism and to bring awareness to churches into being pastoral institutions that can offer hope to people with Albinism.

It is also intended to contribute to addressing factors hindering rearing and caring for children with Albinism. This study sought to establish well effective, efficient, and pastorally enhanced communication, which will be of great benefit to families and especially mothers who give birth and are compelled to rear and nurture children living with Albinism.

### **1.7. Research Methodology and Design**

The methodology is the systematic, theoretical analysis of the methods applied to a field of study. It comprises the theoretical analysis of the body of methods and principles associated with a branch of knowledge. It encompasses concepts such as paradigm, theoretical model and phases, and quantitative and qualitative techniques.

To be able to achieve the aims of this study, the qualitative method of research will be used as opposed to the quantitative.

Babbie describe the qualitative method as the nonnumeric examination and interpretation of observations, to discover underlying meanings and patterns of relationship, whereas a quantitative as numerical representation and manipulation of observation to describe and explain the phenomena that that observation reflects (2006:388)

The qualitative methodology will be used for this research. This method provides the researcher with the opportunity to study the selected topic in-depth, openly and analyse the details identified with an attempt to understand all categories of information that emerged from the data (2011:47). Whom are you quoting here?

In agreement with Neumann, however showing a certain alteration McMillan and Schumacher define research methodology as a complete research process, research approaches, procedures, and data collection used in a study (2001:74).

This study has been undertaken as qualitative research because qualitative research allows the researcher to interact with the participants with interviews. The study aims to investigate whether the perceptions, misguided beliefs and myths exist about the care of children or persons living with Albinism.

The researcher will use a censured theory to analyse data. Interviews will be conducted on groups and individuals, whereby every interview reviewed and evaluated will be used to establish whether the collected data is still in collaboration with the topic. This process is proper in collecting, storing, and analysing data, which will end up being relevant to the problem.

By reviewing the literature, the researcher hopes to come to a deeper understanding of the key phrases of this research: Albinism/Albino, care, children /child, from cultural perspectives and the different fields of study like Psychology, Sociology, and Anthropology

My epistemology search will heavily rely on the information given by the co researchers through interviews. The secondary literature alongside the data collected from interviews will allow the researcher to assess the impact that the rejection has done as well as the copying mechanism that the church might have. On the theory of caring, the researcher will employ Wimberley in Relational Refugees who stated that Children imitate behaviours and learn values from the adults who care for them. In the absence of relationships or healthy, clearly transmitted values, children struggle. They become what one could say, relational refugees. Ministerial leadership positions likewise need someone to imitate and learn from, like a mentor. This copying of behaviour, ideas, attitudes, lives, examples, and ministries of significant others has a long legacy in communities. Most models of liberation have ignored the significance of caring and supportive relationships for the liberation process. Yet ministry occurs in contexts where, increasingly, cross-generational, extended family and church relationships are lacking.

Such nurturing relationships where mentoring occurs and where values are handed on are often stained when the weakening messages of racism are internalized without being countered. Practical methods of ministry, Wimberley suggests are such that one must attend to the ways these messages are learned, and work to counter them by ensuring that there are no relational

refugees. The relational theory offers a structure from which to understand and treat the interpersonal legacy and severe childhood trauma.

In addition, within the theoretical framework to be employed; will be of Nick Pollard's theoretical model of "positive deconstruction" as explained in his book *Evangelism Made Slightly Less Difficult*. He is journeying with the damaged, to help them to positively deconstruct the bad that they experienced.

With the study, the theory will be employed to assist the families, the clergy, and communities to constructively develop new human paradigms of seeing persons with albinism as individual human beings. Lastly, Gerkin will provide a recommendation for the church leadership. Gerkin's model of shepherding will be found from "Introduction to Pastoral Care" where he identifies four models of caring:

- a. The Pastor as a shepherd of the flock
- b. The Pastor as the mediator and Reconciler
- c. The Pastor as a Ritualistic leader
- d. The Pastor as Priest, Prophet, and a Wise Guide.

In this investigation, the researcher will be dealing with caring theories in a particular shepherding of the flock. Moreover, how important are pastors to be ritualistic leaders. This is where the image of God shall be described in such a way that people living with Albinism can care for themselves. They will see themselves not as fewer humans by their conditions. A new approach of deconstructing perceptions, misguided beliefs, and myth will be established, and through Gerkin's methodology will be assisted to rebuild their lives anchored on Christ, the liberator in a way that they construct new people in themselves. More on these two methodological frameworks will be further explored in Chapter two.

The population that has been considered for the study is the families of such persons, clergy within the areas of research, and the persons themselves. Only a sample of the population will be considered which will comprise of those who have an experience of being humiliated, hurt, or ostracized based on their pigmentation like Gobakwang.

### **1.7.1. Data Collection**

Mouton, describes data collection as the source in which direct observation methods like systematic and participant's observation or indirect observation methods like questionnaires and interviews are used and can be controlled by statistical techniques (2017:144).

The research technique to be used is mainly of data collection from written sources, followed by an in-depth literature study review in a form of comparative study relying on written sources and partly on questionnaires to be developed for empirical research. 20 samples will be selected from the community, which will comprise of adult children at the age between 18 and 35 both men women. Finally, the researcher will interview some of them to create a new way of caring for those who are rejected by the community.

### **1.7.2. Literature review**

Borden and Abbott describe literature review as a systematic, plain, and reproducible method for identifying, evaluating, and synthesizing the existing body of completed and recorded work produced by researchers, scholars, and practitioners (2008:7).

It is a summary and evaluation of available information on the research topic, and then based on the findings; the researcher might propose research for further study.

A literature review is the most important element in any research study. According to Corey (2008:1), the Literature review provides the researcher with an opportunity to explore other studies conducted in the researcher's area of interest.

The researcher will review the views of different authors and their understanding of the concept of albinism, pastoral care methods, and how communities' perceptions, misguided beliefs, and unfounded myths affects caring for this group of people. The researcher will also use policies from government journals, reviews, and other publications available that are related to this study because there is no actual literature to back up this research.

The following sources will be consulted:

a. Both primary and secondary sources: These will be specific works of literature that address the topic in depth and therefore provide the required information.

b. The general sources of information will be used to guide the researcher to where more information about the work of caring for children with Albinism can be researched in other fields of study and how can they be merged with pastoral care and counselling as a discipline. (Wikipedia, the free encyclopaedia) (Retrieved 03 March 2016).

c. The electronic media and internet information will be consulted. However, the researcher will be cautious to employ only the information that is scholarly credible, and easily verifiable.

### **1.7.3. Interviews**

Empirical research will be utilized for verification of different independent views; however, a small number of families with such children, churches, or religious groupings with such members will be requested to give their experiences from semi-structured interviews. The locations or areas that the research will be conducted will be around Rustenburg near Phokeng and surrounding villages.

## **1.8. Research Outline/ Format of the Study**

1.8.1. In **Chapter 1** the researcher will outline what forms the basis of the study and how the researcher intends to conduct the study. After the introduction, the researcher will give a brief background and all the linkages and components, which are of essential importance to this study.

1.9.2. **Chapter 2** will focus on a literature review to determine views of different authors on the original definition of the concept “*Albino*” and “*Albinism*”. Care of such persons from other health disciplines against lack of pastoral care and support service to the family in general and the child with Albinism in particular. The researcher will compare and contrast the views of these authors to satisfy the objectives of the research topic. The researcher will evaluate the relevance of the arguments and information to the study.

1.8.3. In **Chapter 3**, the researcher will identify the sample for the research from the chosen population. Once the sample has been identified, the researcher will introduce the chosen research methodology.

1.8.4. In **Chapter 4**, and **5**, the researcher will discuss the results of the analysis; linkages will be made to other sources studied during the research. The results of the analysis will be compared with the objectives to confirm if the objectives and the research question of the study

were addressed. In chapter five, the researcher will discuss the findings, recommendations, and conclusions of the study will be provided.

## **9 Preliminary Conclusion**

The significance of this research is the pastoral care and support service to the child or children living with Albinism and their immediate families. This is crucial for interfaith communities especially the Christian groupings as the researcher comes from that background and this is purported to harm pastoral care and support as a service delivery element within broader Practical Theology. There is a continuing thread of concern from some sources that churches should provide pastoral care that is more effective for the church members and the surrounding communities.

Goodliff attests to the statement above by exploring the nature of pastoral care in the post-modern society that: “Pastoral care will then include not only the healing of the sick of soul and mind, but also the direction and guidance of all members of the community as a vital element of its task, the proclamation of the ethical ways in which reconciliation takes place, and the sustaining of the community in worship, attention to scripture and compassionate love” (1998: 98-99).

In other words, the church has to avail itself for pastoral care and support services even to the families of children with Albinism. In chapter two, the researcher will conduct a literature review to understand the views of other authors on the study. The Chapter will also revolve around pastoral theology which according to (Allen: 1991) is defined as "religious truth to spiritual needs." When talking about pastoral care and support services of people affected with Albinism, we refer to the spiritual guidance in the form of support and care a person can receive from a member of the health care provider in this case being a pastoral care practitioner in the community hospital, church or relevant and appropriate environment. Historically according to Browning pastoral care has had two main functions, firstly incorporating members into the life and discipline of the church and secondly, assisting persons who were handling crises and conflicts and personal and spiritual problems (ibid.1976:43).

## CHAPTER 2

### LITERATURE REVIEW

#### 2.1. Introduction

According to N.O.A.H (National Organisation for Albinism and Hypopigmentation), Albinism is a genetic condition most often characterized by a lack of pigmentation in a person's hair, skin, and skin. It is caused by inheriting a recessive gene from each parent and occurs in approximately one in every 17,000 person; U.S.A and may be around the world ((N.O.A.H. 2008:29)

A person living with Albinism faces several challenges throughout their lifetimes. One of which is the stigma they have to face in their daily lives. Stigma or stigmatization is referred to as social rejection. Individuals who are often been stigmatized or been ignored and rejected by others because there is certain labelling they are carrying. It may also be that their physical appearance indicates that they belong to a specifically labelled group. Most particularly stigmatization of People with Albinism is often associated with myths, which might involve danger or death. It is believed that their body parts can bring luck.

In this chapter, the researcher will give a brief background in reviewing the views of different authors and their understanding of the concept of albinism, people living with albinism, pastoral care, and how the community's beliefs and perceptions influences the families with such persons. A literature review is the most important element in any research study undertaken because it brings information that was found from the other scholars to reveals the truth about the research. According to Corey (2008:1), the literature review provides the researcher with an adequate opportunity to explore other studies conducted in the researcher's area of interest.

Borden and Abbott describe the literature review as a systematic, plain, and reproducible method for identifying, evaluating, and synthesizing the existing body of completed and recorded work produced by researchers, scholars, and practitioners. Therefore, the researcher needs to go through other people's studies to compare and validate the information (Borden's and Abbott, 2008:7)



It is a summary and evaluation of available information on the research topic, and then based on the findings; the researcher might propose research for further study after grappling with ambiguous and uncertain variables within the theoretical and conceptual frameworks of scholars and other resource persons.

The researcher will use policies, journals, reviews, and other publications available in this study. This literature will untangle data on people living with albinism, (PLWA), their social settings, and how Albinism can become a complication in their social existence.

The chapter will also explore what Western and African scholars are saying about Albinism, with the approaching guidelines that will help the researcher to investigate.

According to Mswela, South African living with Albinism is among the most marginalized and vulnerable of the country's citizens. Yet very little attention is given to protecting them from human rights violations, threats, and violent crime. In her research, she mentioned that, although the extent of violent crime targeting African countries, new evidence indicates flow in violence against persons with Albinism. Mswela. Explain the vulnerability of these people requires immediate attention before it spread out of control. (2017:114-133)

The church in its quietness has said nothing to voice out their stand. The above information confirms that people living with Albinism are faced with life-threatening challenges; this research will therefore assist in voicing out for their help from the church community.

. The following guideline will help to guide the study:

1. The hypothetical and abstract framework of the concept "*albinism*" will assist the researcher in deeply comprehending the analysis of the literature done around the concept of albinism.
2. In what follows, the researcher will first examine the *etymology*, which will later thoroughly be the definition of the word "*albinism*" and it is various broad and narrow definitions and then suggest a more adequate definition that will bring us to a better understanding in the African context and global perspective. This chapter will treat the following statements

1. Conceptual difficulties that the researcher encountered in defining albinism and albino.
2. Furthermore, the researcher will examine opinions on the causes of albinism and then situate the problem in the setting of a community and the care that is expected from both community and church.
3. Finally, the researcher will situate the problem of albinism, in the community and church context, in selected areas of Rustenburg and Phokeng villages, where quite several families with such children are living. It is in these areas where it is allegedly said that discrimination against people with albinism has been in the upward trend since cultural beliefs and myths are rife.

## **2.2. Definitions of Albinism/ Albino and Conceptual Framework**

According to Smith's hypothesis, "*Albinism*" is "a complicated process with various inter-related and difficult factors and is affected by dynamics such as culture, myths, beliefs, gender, race, and socio-economic status" (Smith, 2002:84). The researcher believes that the above-mentioned process which in other instances is just a procedure to show how different situations react to the matter of Albinism. And in this context being born with albinism is like being stigmatized and discriminated against which involves labelling differences and separating 'people' from 'others', in this context, it is the seclusion of people with Albinism from "us" who believe that through our skin pigmentation, we are better than those living with Albinism and they are not normal.

The process as mentioned and described by Smith above creates shaming and discrimination and often results in isolation or death thoughts. It is very important to note that in the Gobakwang case, thoughts of death did not occur. It was only believed that they do not die but disappear, as such the grandmother and other family member's isolated him based on the community perceptions.

The researcher holds a view that it can become easy to discriminate against people living with Albinism (LWA) because people think that they do not possess the qualities that make them worthy of respect and dignity. This is what Ntina (2008) said that they are being perceived as sacrificial lambs, of which is a Biblical metaphor, it is for someone that is for a good sacrifice of others. In this case, these individuals are being mutilated. Legal and human rights authorities are

echoing, but they are still victims of brutal attacks. People act on their beliefs against the people living with Albinism and this often creates active discrimination and human rights abuses. All the above are suggested in the capacity as the researcher as some have occurred in the area where the investigations towards the study took place.

### **2.2.1. A Working Definition of Albinism/**

This is an ongoing study; the following conceptual and hypothetical framework will be used while investigating factors affecting P.L.W.A.

Mukwenda (2018) describes Albinism as, “rare genetic conditions that affect the pigmentation of the retina and skin”. According to his statement, ‘People with Albinism worldwide end up experiencing stigma and negative results of unconventional physical appearance as well as visual impairments. The medical and social literature has focused extensively on the genetic side, therefore P.L.W.A, have rarely an opportunity to tell their stories, their sorrows, and triumphs’.

This research, therefore, seeks to attempt to fill the gap left in pastoral care.

Mukwenda and Penda framed their study around Coffman's theory of stigma, spoiled identity, and disability that concentrated on the "normal" as being the problem. In their work, the participants revealed victimization from various sources including students, teachers, employers, colleagues, strangers, and medical professionals. This research will then focus on helping to journey with them towards rebuilding their lives on the purpose that God has intended them.

(Retrieved 10 April 2020. [www.wwjmr.com](http://www.wwjmr.com))

Their focus was on the strategies that respondents have used in coping with these adversities. Their results identified methods of reaction and response to the discrimination against P.L.W.A. However as mentioned before this research as ground-breaking on a Pastoral Care, will depend on existing sources to gather the information.

### **2.2.2. Conceptual Framework.**

The conceptual framework will be effective in this research because it defines all factors on matters affecting P.L.W.A. and their families.

The framework starts by exploring the word Albino, Stigma, and then followed by circumstances like those that of Stigma itself, discrimination; attitudes, and labelling or skin colour can be used in identifying them. The explanation will end with a child and Pastoral care.

## **I. Albino/ Albinism**

Albinism is an inherited condition; a person with Albinism is characterized by an absence or reduced pigment in the eyes, skin, and hair. Lund further pointed out that the inherited genes that do not make sufficient melanin, which is required to develop the retina, which results in visual impairment (Lund *et al* 2007)

Furthermore, a P.L.W.A can be said to have a white skin condition, white hair, and pink eyes, eyebrows, and eyelashes are white. The person has a rapid eye movement or jerking of the eyeball, which is a result of a condition known as nystagmus. Nystagmus is an involuntary movement of the eyes that can cause fatigue when carrying a visual task. P.L.W.A may have a poor visual acuteness, sensitivity to light and sunbeam, skin lesions and cancer, and lack of binocular vision. This may lead to a social problem and communications because most of the time they get second-hand information. They also have mobility problems. They may have little experience with the environment due to social isolation.

(Retrieved 5 March .2020.[www.wwjmr.com](http://www.wwjmr.com)).

It is therefore clear that Albinism has the same condition in all cultures and they all go through the same type of emotional treatment, the difference is in the physical treatment, different cultures practice their understanding way in living with them.

## **II. Stigma/Stigmatization.**

Stigma is a powerful social process of devaluing people based on a real or perceived difference, such as class, race, and behaviour. A dominating group to create, legitimize, and perpetuate social inequalities or exclusion that uses stigma. Stigma always leads to discrimination, which will lead to an unfair and unjust treatment to an individual based on that socially identified status (Retrieved.10. April 2020.[www.wwjmr.com](http://www.wwjmr.com)).

The stigma attached to P.L.W.A. is usually a source of great anguish and shame, which Wimberley define as being alienated from the community, which produces a sense of being unloved, where people often seek social status and material wealth to satisfy the resulting need for love (Wimberley 2001:21).

Most cases of Albinism are from not wealthy families, because of a stigma they may not have a social engagement or enjoy themselves in public places. According to Mulemi and Ndolo, P.L.W.A mostly suffer social exclusion, which they describe as a process of exchange in the whole society that has a negative attitude for some people. (2014:21). The social exclusion results in failing to integrate some people in family and employment arrangements. The exclusion can sometimes be visible. Therefore, this exclusion can result in disadvantaging these people in having poor skills and being targeted in high crime and family breakdown.

The perception that P.L.W. A's body parts can be magical does not only discriminate and exclude them but also create a sense of anxiety, fear, and denial of freedom and movement and association (Mulemi and Ndolo .2014:21). In this regard, these people are mostly very aggressive in responding to a certain individual approach.

### **III. Discrimination**

Discrimination is showing of favour, prejudice, or being bias against any arbitrary grounds. Example on basis of sex, colour, culture, and language (Albarracin et al: 2005).

“Discrimination against P.L.W.A is reportedly a worldwide issue. While the degree, scope, and severity vary from country to country, the common threat is bullying”. (Retrieved 2020.June 18. [www.wvjmr.com](http://www.wvjmr.com))

Victims of discrimination suffer anxiety that might lead to depression, this can lead to either aggression or isolation of a victim, in many cases, they fall victim to abuse as they become vulnerable. Nevertheless, the behaviour depends on the type of discrimination. Wimberly describes this as “A lack of interpersonal bonds that generate or activates the deep feeling of humiliation in all people this behaviour these feelings may cause a person to strike in violence” (2000).

### **IV. Attitude**

An attitude is defined as a psychological tendency to view particular objects or behaviour with a decree of favour. Attitudes are understood to be formed through a process of individual subjective evaluation (Albarracin *et al*: 2005)

Selepe in the study of teenagers with Albinism stated that it is the result of a negative attitude. Therefore, the negative attitudes experienced by P.L.W.A. due to their skin colour are unfair. Being called names that demean them humiliate them (2007).

## **V. Labelling/tag/ Identifying**

Baker describes labelling as a process of creating a description that identifies a person who differs from the norm. A tag or label is given to anyone different in some way from others. A label is usually degrading in nature. The very visible difference in the appearance of P.L.W.A., leads to bad labels and those results in poor social integration among the next person. Countless myths and superstitions surround this condition led to stigmatization, rejection, and a lack of understanding of Albinism (Bakers *et al.* .2010)

Based on the above information it is clear that stigma and conceptual framework can be used as one of the models in identifying the above factors that are affecting P.L.W.A. in South Africa. Thus, the factors mentioned above are forming part of the evidence that care is needed for P.L.W.A. Care that Maake (2005) regards as to be engaged in the task of restoring the wholeness of human life by being co-workers with God in the primary task of perfecting divine creation.

Most of the stigma-based attention visited upon P.L.W.A is maintained by, often unspoken, societal rules that can never be proven, which have resulted in widespread and structural discrimination against them. Some of the most serious human rights abuses faced by P.L.W.A to date are physical attacks. These are namely death, dismemberment, sexual assault, and mutilation.

Studies around Africa from WHO (World Health Organisation) to date, give a record of 305 of such attacks in 23 countries have thus far been reported and recorded. Most physical attacks against P.L.W.A are not reported because they tend to occur in the mystery of cultural infanticide. As it has been stated in the first chapter that, *as soon as midwives realized that the child has Albinism, they would say he/she came up tired.* Also, Prof J. Makumbe, a political Scientist confirmed on the documentary he recorded with Charlotte Metcalf: that he was almost strangled at birth by a midwife, but was saved by his mother (Metcalf: 2003:136).

This also tends to be covered in the "code of silence" of witchcraft practices. Some of these practices encourage the murder of P.L.W.A. Based on the belief that they are ghosts and not humans; and that their body parts can be used in potions to bring wealth and good luck to the end-user. (Retrieved.05 June.2020 [www.hrw.org](http://www.hrw.org))

Epoch Times told the story of Nwokocha, a Nigerian- Canadian photographer, has twins, a boy, and a girl. One twin is born with Albinism and the other is "normal'. She wrote to "Love what matters.' I waited for a few seconds for someone to tell me there was a mix-up'. For all her mother could see, Kachi looked as though she was born to fair-skinned –parents, perhaps she's just very fair in complexion; I thought, "the mother recounted'. The mother recounted. Albinism never crossed my mind as we had none in my family as far as I could remember ". Her faith allowed her to see that the difference was only skin-deep. Since then, Nwokocha has embarked on a photography project to show Kachi how beautiful she is "so she would see pictures and believe in herself".

"I was worried about if people are going to accept her or if she was going to be a victim of bullying" explained Nwokocha, though she lives in Canada, people living with Albinism are subject to social discrimination in her native land of Nigeria. She said she asked herself" why me? Why must I have an Albino baby? Why did I get a black and white child?" (Epoch Times: accessed .28 April 2020)

Nwokocha story is one of many that are not said, but it is happening to many of the parents who gave birth to these children. The fear that they experience before even showing their children to the world is overwhelming. The hostile behaviour of a mother can also introduce some sort of danger to the child. According to the story, Nwokocha and her husband did not know the history of Albinism in the family. These questions asked are real and that indicates the importance of pastoral care and counselling.

What remains is how to deal with this issue to answer the question: how should P.L.W.A be protected? This research will attempt to answer this question in chapter 6, the chapter that is on healing

### 2.2.3 Some Conceptual Difficulties

While the status of their look is being questioned, they have their struggle as well. The practical problems associated with living with albinism in southern Africa are many. It is a fact that, people with albinism are vulnerable to sunburn, long-term skin damage, and have an increased risk of developing skin cancer. In other words, a reduced visual sensitivity associated with the condition, also makes daily life difficult. However, with proper health management, eye care facilities, and the provision of skin protection creams, albinism can be managed successfully.

The most important sun protection strategies are low-cost, such as wearing appropriate protective clothing and sun avoidance, particularly during the middle of the day. Hence, Gobakwang was kept in the house. Protective creams and prescribed glasses are for temporary measures; also, the family did not have any idea how to find them.

“Apart from myths associated with albinism in South Africa and other parts of the world, society also has a profound influence on the lives of people with this condition, from the moment of their birth until their death. The beliefs and superstitions surrounding the condition affect family life and interfere with access to education, employment, and marriage.” (Kornberg et al.1997 and Lund *et al.* 1997).

Drawing on a common interest in albinism, specialist research interests, and recent multi-disciplinary studies and research carried out in South Africa and Zimbabwe, these myths were examined and traced to the impact on the lives of people with albinism. The actuality of living with the condition in parts of present-day southern Africa was reported in the first-hand accounts of people with albinism. (Retrieved 07. May 2020. [www.hrw.org](http://www.hrw.org))

This indicates an awareness that needs to be made about Albinism. That people living with Albinism need to be considered as humans made in the image of God. They have to be counted as individuals amongst the so-called "normal" people. All they need is to be loved by people they live with.



#### 2.2.4. Theoretical Framework.

Wan quoted Coffman's model of the 'normal', which provided an analytical framework for theorizing factors by using the aspect of stigma, labelling, attitude and discrimination, and skin sensitivity. Concurring with this analysis, it is clear that Albinism is has a common factor that affects their livelihoods. He defines a stigmatized person as one that possesses an attribute that is deeply discrediting. He refers to those who are stigmatized as the “Normal” (2010).

He further mentioned three types of stigma. According to him, the following information was identified; -

An abomination of the body is a stigma, because the carrier has different types of deformities, conditions such as:

- a) Blindness and Albinism.
- b) The second type is called blemishes of individual character, of which the person is said to be having a weak will, unnatural passions, dishonesty and this could be due to the condition of Albinism.
- c) The third is called tribal stigma of race.

He also has labelling as stigma, which he describes as a mark assigned to an individual. Coffman discovered that labelling attached to any individual condition is crucial and influences the way people think about individuals. However, P.L.W.A may not have a problem of being called Albinos, but stigma can lead to them losing peers

(Retrieved 13 June 2017, [www.tadfondline.com](http://www.tadfondline.com))

It is therefore important that the attention of how people react to them be taken into account.

There is a severe lack of thorough empirical research into understanding the lives of P.L.W.A.

Their voice concerning how their rights are being enacted and are being denied. The difficulty they face and what might be better supported, empowering, and protecting them, has to date been denied. The available evidence on the traumatized lives of the P.L.W.A has been predominantly unattended, with a little attention being given to the unique experience of the minority.

Exploring what is known about Albinism within an included disability and rights lens, will help the majority to identify the structure and berries faced by this group and suggest possible ways to overcome them. Chatting to one pastor about how they are being treated has shown that, there is ignorance on how these people live. He passively said' I have known these people but we are just

living normally with them". It looks so normal to him; he even made a joke about them, like forget about them.

### 2.2.5 Etymology

Etymology is defined as the study of the origin of words and how their meanings have changed (Retrieved 10 February 2020 [www.etymonline.com](http://www.etymonline.com))

Several literature arguments are propounding the view that is also propagated by Martins that: "Albinism is said to be the oldest anomaly ever recorded Origin of the word "albinism", is from the Latin, *albus*, meaning “*white*”, or “whiteness” not associated with purity. According to Martins, it might also mean, “clear”, as in no colour or features. The 17th-century historian named Balthazar Tellez a historian and missionary coined the modern word “albinism”. Martins primarily coined the term “*albino*” meaning white Negro when he saw tribe members along the coast of West Africa (Martins, 1975: 48-59).

However, the origin of Albinism in Africa seems to have not been traced that far, according to Mulemi and Ndolo (2014) "naturist and evolutionary traced P.L.W. A, from the 18<sup>th</sup> to the 19<sup>th</sup> centuries. These people appeared unusual because they stayed indoors or in the caves until dawn due to the harshness of photophobia. This may contribute towards the increase of the mystery and unethical rumours about their existence. In this regard is clear that P.L.W.A are victims of the Biological condition in which the body fails to produce due to the absence of pigmentation to cover the inner layer of the skin" (Mulemi and Ndolo, *et al* Robin, Jolly, and Ploy)

P.L.W.A are born to normal parents who live amongst the community who may not know how they are born and are dictated by culture to act in certain cruel ways.

His earlier works include "*leukoethrope*", a Greek word for white, or *leukoethiopians* meaning “*white Ethiopians*”. According to the author of the article continues to highlight the fact that there were different names called or used to call “*albinos*”, such as “*moon children*” since until sunscreen and sunglasses became available, they were not able to spend a lot of time in the sunlight and went about at night.

However, in the article by Charles Martin, *The White African American Body*, gives a view that another word is '*dundus*' from Africa or West India "*meaning a ghost or spirit person: a body walking around without a soul*" (Martins, 1975: 48-59).

There were further several words mentioned by Martins that are related to whiteness, featurelessness, and nothingness such as albatross; (a white bird), album; (white or blank pages), blank, blond, blanch; (a pallor achieved when blood leaves the face) bland, blizzard; (a whiteout) and bleach). The author postulated the idea that based on the letters "*b-l-a*" and "*a-l-b*" are very much related in use and meaning" (Martins, 1975: 48-59).

Martins quoted the Midrashic accounts (The term Midrash means exposition or investigation). It is also referred to as used in two senses that it is a mode of Biblical interpretations that is prominent in Talmudic literature. (Retrieved 26. March.2018.Wikipedia.org), stating that the famed Noah of the Old Testament at birth had hair as white as snow and eyes like the rays of the sun. His father thought he was an angel and fled from the baby's presence, frightened for his very life. The father was persuaded by his father to return to his son's side and care for him. (Martins, 1975: 48-59).

Clearly, Albinism is something that has been there since the beginning, but it must have been known by another name and but by the above physical description; it matches the description of a person with Albinism; hence their existence has always been a mystery. God gave them an equal task as any other human being, and this can only mean that being extraordinary different serves the same purpose in God's plans.

#### **2.2.6. Biblical Evidence of White Skin**

The word "white skin" is used in this research; it is used to describe how these people were literary called, that is according to how they look. Welsing also used these words to demonstrate how in many cases of individuals turned white has occurred in Jewish biblical history.

The researcher is also using the same example to describe them; they had a white appearance, and they were described as they are. According to Welsing: "When God wanted to show Moses a miracle, he turned his hand "white as snow;" then God turned his hand back again to its original

colour of black”. He further indicated that;” in ancient Israel when a man had a white spot on his skin or white or yellow hair, or white skin somewhat reddish, he was pronounced unclean.

All people who were victims of this shameful disease were isolated outside of the camp or city and segregated.” Dr Cress Welsing, revealed that, ’ white people are Albino mutant”, in her opinion, the course of white skin is Albinism, which is genetic, defects of black people.

(13 June 2017, [www.geocities.com](http://www.geocities.com)).

This is evident how deep the matter of skin colour was during the biblical era; matter of whiteness or "albinism" was part of the societal dialogue. This indicates that God was proving a certain point, however, not necessarily on a matter of race. The skin texture took two or more depictions and for the Jewish people; it had a meaning that is not necessarily the same with us today. Having a white skin amongst the dark coloured people has always raised an unstructured talk that resulted in having culture having to decide and dictate the future of these people.

Welsing has made a thorough knowledge of the issue of Albinism and has hit the nail on the head with her book.” The White Race has the genetic inability and absence of melanin to produce the different skin pigments seen throughout the world. That absence of skin pigment creates the inability to produce colours” (1991:23)

As a result, “uncoloured or white skin is produced. White Race genes are at a recessive global juncture. Recessive genes outline body characteristics that are covered or not articulated when a contrasting dominant black or brown gene or trait is present. The black/brown genes create people who have curly hair and whose skin is easily tanned

Therefore, white-skinned people came into existence thousands of years ago as the Albino malformed offspring of black-skinned mothers and fathers in Africa. A sizable number of these Black parents produced, rejected, and then cast out of the community their genetic defective albino offspring to live away from the normal black skin-pigmented population. There were colonies of albinos formed which eventually migrated northward to Europe, to escape the intensity of the equatorial sun of the Southern hemisphere (1991 23).

According to Dr. Welsing, it is possible that during the Biblical Times, Albinos were ostracized. The same thing is happening today when Albinism occurs in society. Their own families

especially in Black families where the difference in skin colour is more distinct, ostracize albinos. The ostracizing of Albinos during Biblical times is the only logical explanation of how the word “White Race”, came into existence or how people were being segregated, that is according to the way they look (1991:23).

It is evident now that although the word albinism might not have been used as it is today per se, people, nevertheless, have been using other phrases to express the same meaning.

### **2.2.7 A broad definition of Albinism/ Albino**

Broadly defined Albinism may be understood as a "condition that is genetically inheritable that is characterized by Hypo melanosis. Hypo melanosis is the patent reduction or absence of melanin involving the skin, hair, and eyes". Albinism may be described as a genetically recessive trait; therefore, both mother and father must carry the gene for it to be passed on, even if they do not have albinism themselves.

It is the researchers' view that Albinism is not and cannot be defined singularly, thus it has a broad approach of difficult elements that add up into its description.

“When both parents carry the gene, there is a 1 in 4 chance at each pregnancy that the child will have the condition. Some rare instances of albinism may be limited to the eyes (ocular albinism). In this case, the person has light-coloured eyes but normal coloured skin and hair. Another rare type of albinism is the type marked with Hermansky-Pudlak syndrome (HPS). HPS is a type of albinism characterized by platelet dysfunction and prolonged bleeding. All persons with HPS -- even though they display a wide range of visible pigmentation, they have a visual impairment just like the general population” (Retrieved 12. July 2017, [www.underthesamesun.com](http://www.underthesamesun.com))

Albinism results from the inheritance of recessive gene alleles and is known to affect all vertebrates, including humans. It is due to the absence or defect of tyrosine, a copper-containing enzyme involved in the production of melanin. The albinism syndrome shows parallels with sickle cell anaemia. The carrier of the sickle cell mutation is at an advantage in regions where malaria is hyper endemic, which includes large areas of Africa (Retrieved 12, July 2017, [www.underthesamesun.com](http://www.underthesamesun.com))

Therefore, the researcher's understanding in this context is that there is a perception in regional areas that have influenced the chromosomes of the parents, thus; the child is born with Albinism. However, this is a notion that can still be discussed in depth in the biological studies and reproductive systems.

### **2.2.8 Narrow Definition of Albinism and Albino**

N.O.A.H, describe the word Albino as a white person. It is derived from the Latin word “albus” meaning “white”. Since the 17th century, the word Albino has been used to describe living creatures with Albinism, having little or no colour in the skin, eyes, and hair (2008:29).

For humans, the term people living with Albinism is preferred by some, because it emphasizes that these are people like anybody else who lives with a special condition: "Albinism". We will use both terms interchangeably because language can shape ideas and create reality. Therefore, we should avoid using words like "Zeruzeru" meaning double zero or a worthless person (Sullivan.2013:7.). Using this word is very impolite and singles out Albinos in a negative and unjustified manner.

### **2.2.9 CLASSIFICATION OF ALBINISM AND COMMON ASPECTS**

“Albinism is a group of a genetic condition that results in little or no production of the pigment melanin. (Retrieved 28. March 2018, [www.albinsm.org](http://www.albinsm.org))

It is a common individual with Albinism who is very sensitive to sun exposure and is prone to developing skin cancer.

According to Albinism society, “all forms of Albinism course problem the development and function of the eyes; visual impairment is common amongst them.

Albinism is classified based on which muted gene coursed the disorder”.

“There is no cure for Albinism; the treatment can be visual rehabilitation.

Many P.L.W.A, need prescriptive lenses by an ophthalmologist.

Surgery may be recommended to minimize nystagmus; it can also be recommended to correct the strabismus.

This might make the condition less noticeable, but not improve their vision.”

(Retrieved 28. March 2018, [www.albinsm.org](http://www.albinsm.org))

Some people with Albinism may experience torment at school, workplace, and elsewhere through name-calling and bullying. This must be checked and reported at the earliest opportunity. Children should be encouraged to be open about their Albinism and it would be very beneficial for them to have contact with others with the condition as a means of encouraging good self-esteem because the environments can create a danger to them.

The unfolding stories commencing with one of Sullivan and the one narrated by the researcher on Gobakwang are within the African continent but different countries, their differences are minimal, but their painful similarities are a condemnation to the pastoral world as in both of them there is no mention of the pastoral care and support services.

As a human description of a young innocent boy born with Albinism in a little village of Mwanza in Tanzania as articulated by Sullivan.

For Sullivan, this was an unbearable act, that devastated not only the family focus, however, even the extended family as a father who resolved to leave his family, believing that the birth of this child is a bad omen or an act of bewitchment. For one member of the family said after the leaving of the father, "we used to be fine here, very fine; father was able to keep the farm running through worse droughts than this. He would have not left if it was not because of this stupid ghost boy, none of this would not be happening" (2013:7).

The story continues to highlight the severity of the situation of the young innocent boy when both certain family members and villagers resorted to derogatory names such as "Zeruzeru" (a Swahili derogatory word for nothing or zero). Certain members of the family could not cope, how much more a small child that is not even aware of the happenings around it.

Summarily, for Sullivan, the wicked act in Tanzania does not stop when the child becomes an adult, however, the severity of it is captured when now the person with albinism is hunted like an animal to be killed or murdered, propagating misguided beliefs and myths that their skin, body parts, and blood can be used as "muti" to bring charm and good luck to businesses and life in general.

The researcher has observed that matters of hardships for persons with Albinism are not methodical, however; they turn to develop themselves into sub-cultural elements and project the whole culture of that community as cruel, inhuman, and humiliating.

### **2.3. Classifications in the African context**

Ingstad and Whyte state that “Although cross-cultural work in anthropology and disability studies have highlighted the fact that the western definition of disability does not necessarily have a clear correspondence to how people define disability in other parts of the world” (1995).

However, Groce points out that all societies and cultures do have their explanations of why some individuals have physical differences as compared with ‘the norm’ (1999).

As underlined by Ogechi and Ruto for instance, although persons with a disability in Kenya are usually considered ‘normal,’ other villagers do try to understand the reasons why disability occurs (2002).

Because of a lack of understanding of Albinism, it can be classified as a disability because many people do not know how and why these people are different. Ignorance also plays part in this, as people with high knowledge tend to ignore the behaviour by the community because it does not affect them. For the fact that P.L.W.A is quiet about how they are feeling, it means that they do not suffer. This has therefore developed into a shame that Wimberley has expressed by saying, “For some people ‘*shame*’ is so deep that they cannot envision themselves as part of the plan of God” (1999:58).

For disturbing matters to be taken as “*Normal*,” it can bring sorrow, because something that people regard as “*normal*” ends up being death.

#### **2.3.1. Tanzania**

“Tanzania has one of the highest rates of Albinism in the world’. (Retrieved 17 March 2018, [www.underthesamesun.com](http://www.underthesamesun.com))

It is alleged that they are targeted in shocking attacks and it is motivated by superstitions. They are been regarded as a ghost. Vicky Motetema has found out that P.L.W.A are being killed because of ignorance. Thinking that P.L.W.A are not and be blamed for every natural disaster that is happening is worse than ignorance and cruelty. This also takes everyone back to a lack of knowledge.

According to Mulemi and Ndolo (2014), Tanzania carries the largest number of killings and persecution of P.L.W.A. Because they are still largely characterized by old traditional, superstitious believes that relate to witchcraft. In their recent research, it is reported the highest



incidents of killings and persecutions was reported in the region of Mwanza, Shinyanga, and Mara, this area Christian, Islam, Independent Christian churches and traditional Africa religion are characterizing the context of health-seeking and livelihood. Though the Tanzanian government has condemned the practices of mutilations and killings and has put together mechanisms in place to protect the affected P.L.W.A, the media is still reporting the ongoing killings (Mulemi and Ndolo.2014: 45).

This revealed that available forgoing reviews further affirm the marginalization, discrimination, and persecution of P.L.W.A in Tanzania demonstrate a lack of political and social solution. This affirms that beliefs, attitudes, and superstition still dominate the factors influencing human rights recognition.

### **2.3.2. Zambia**

Zambia forms part of the borders of Tanzania that is experiencing the incidents of brutal attacks of P.W.L.A. According to Albinism.org," children and P.L.W.A in Zambia are also suffering the same fate as in other parts of the world. Their physical appearance is always subjected to erroneous, beliefs, myths and this resulted from superstitions which favours their marginalization and social exclusion." Witchcrafts related and harmful practices influence most actions including physical attacks and killings, maiming, rape, grave robbery, and human trafficking and body parts.

However, the Zambian Constitutional Court has supported the publishing of a handbook called "Living with Albinism in Zambia". This is the information for children and young people, which is aimed at teaching them about health care and sun damage.

People are encouraged to collect the free distribution of sunscreen lotion and bills are covered by Population and Housing ([www.African-albinos.org](http://www.African-albinos.org).retrieved 2019/9/9).

### **2.3.3. South Africa**

South Africa has people with Albinism that are marginalized and vulnerable in their community. Like all the above-mentioned countries, cultural beliefs, superstitions, myths, and false perceptions about their existence make it difficult for them to enjoy their lives. In most rural areas, there are still killings in the name of rituals for becoming rich. Recent attacks showed on the news about attacks in Mpumalanga, Kwa Zulu Natal, and Eastern Cape show that there needs to be attention on protecting their lives by making awareness of their belonging in the society.

Mswela wrote about the incident in Kwa Zulu Natal with the South African Constitutional ground ruling decision in the case of Carmichete. There are many causes of the killings in South Africa, but few are reported or come out to the media, with the belief in their families when they disappear, that it is “normal” (Mswela, 2017; 114- 133. accessed August 05, 2020, at 14:20).

The 4-year-old boy was reported murdered in Empangeni Kwa Zulu –Natal. This tragedy has recently gained the attention of the international community. It has resulted in several resolutions at the United Nations and African Union levels. It has also received support in declarations and statements of international and regional bodies.

A 20-year-old was murdered in Scabatini, Umhlabuyalingana whereby a 19-year-old was found guilty. The reason for her murder was for muti purpose.

Many cases happen in the rural parts of South Africa, even though the ones that live in urban areas are thought to be safer, it cannot be guaranteed as the markets are all over.

An interview on the S.A.B.C Morning Live (31 August 2015) with Nomasonto Mazibuko of Albinism Society of South Africa, confirmed that P.L.W.A in South African are been hunted and killed by people they know. People like Thandizile Mpunzi who was murdered; the motive was that her body parts could bring luck to people. The abovementioned stories form part of many stories of the P.L.W. A being tortured and murdered. However, Nomasonto mentioned that the discriminations and killings are the results of a lack of knowledge that brings fear to some of the families of these people. She said it is evidenced by the attitudes of the community when they see them; they bring discomfort by going to an extent of pointing a direct arrogance at them. To her statement, the community supports the PLWA when it suits them (SABCNews.31 August 2016)

#### **2.4. Preliminary Conclusion**

The available literature, media reports, and reviews further affirm that the persistence marginalization, discrimination, persecutions, and killings of P.L.W.A, in South Africa and other parts of the world are rife. Quite a lot of authors have engaged diverse communities and surveyed why P.L.W.A are being treated with shame and disgust.

Mulemi and Ndolo, Mswela, many other scholars, and other media channels have done many writings about this topic to some extent on the psychological, medicinal, and sociological phases. Nothing has been done on Pastoral care.

Beliefs, attitudes, and superstitions about P.L.W.A, are the main reasons why they are victims of circumstances. Therefore, the study is set out to characterize the pastoral care viewpoint on Albinism. This will dictate the inclusion of Pastors on seeking knowledge about Albinism and their families in South African.

It is therefore the researcher's view that church communities do not know about caring for P.L.W.A and their families or are being ignored as Nomasonto has said. Nomasonto is one of the founding members of Albinism South Africa; this is the organization that was formed to raise concerns and awareness about Albinism. She said, people chose to select some facts that suit them when coming to issues relating to Albinism, hence when they are being hurt it raises minimal attention and everyone forgets about what happened.

In the next chapter, the researcher will be dealing with research methodology, research design, and all the issues that are related to data collection, interviews, and responses of the questionnaires, sampling variables, and data analysis.

6

## CHAPTER 3

### RESEARCH METHODOLOGY

#### 3.1. Introduction

This chapter presents the research methodology process. An explanation used in this research will guide and inform the process of this research. The chapter will describe the research design, its philosophy, and strategy and time horizon and then follows the targeted population and sampling size including the study framework. The instruments, which are used, for this research will be thoroughly discussed. The chapter will also cover the trustworthiness and data analysis. This will be followed by the "validity and reliability" and the elimination of bias and ethical consideration will conclude the chapter.

#### 3.2. Research Methodology

According to Mouton, research methodology is derived from the Greek words, "*methods*" and "*logos*". The term "methodos" in turn is made up of two words: "Meta" meaning "alongside and "hodos" meaning 'either "a road' or "journey". "Meta-hodos" literally then means "alongside the road" and metaphorically, this means or method of doing something (1996:35).

This means that the research holds various standardized and techniques to pursue knowledge. Research methodology can either be qualitative, quantitative, or even mixed of both, according to Creswell (2009:118). Stanger has a different opinion that; qualitative research methodology only focuses on observing and describing the events to capture all of the daily behaviour (2011:81). It is the suggestion of the researcher to understand both authors to be connecting with the other researches by implying that, every researcher must choose between different options of research methodology, which fall into a broader category like qualitative and quantitative. It is therefore important to observe that the whole process will never be flawed; however, the approach should adhere to laid down guidelines and procedures to come up with a dependable data.

### 3.2.1. Research Approach

A qualitative methodology will be employed in this research to pastorally evaluate the setting of People living with Albinism regarding misguided beliefs and cultural beliefs that have led to them being discriminated against. Several authors have been employed to describe a qualitative methodology. This was done to investigate different author's approaches to this meaning.

Burns and Grove, together with other authors have advised that qualitative research methodology is concerned with the understanding of experiences and behaviour, and the meanings and interpretations that people attach to the experience (2009; 55).

Neumann defined a qualitative methodology, as “Qualitative research is an inquiry process of understanding based on distinct methodological traditions on inquiry that explore a social or human problem.” This method provides the researcher with the opportunity to study the selected topic in-depth, openly and analyse the details identified with an attempt to understand all categories of information that emerged from the data (2011:47).

Walkman explained qualitative data as more around words that cannot be manipulated mathematically and require quite different analytical techniques. Essentially human activities and attributes such as ideas, customs, and more beliefs that are investigated in the study of human beings and their societies and cultures cannot be pinned down and measured exactly (2011:73).

According to Babbie, “qualitative research is a numerical examination and interpretation of observations, to discover underlying meanings and patterns of relationships (2005:387)

Whereas Swinton and Moat define it as a multi-method in focus, involving an interpretative, naturalistic approach to its subjects and matter. (2006: 29.)

It means that all the above authors carry the same idea that, a qualitative research study in their natural settings, attempting to make sense, or interpret, a phenomenon in terms of the meanings that people bring to them. It is appropriate to apply this method in this context, to understand and assist in evaluating the program that will attend to the spiritual needs of the people with Albinism and their families.

### 3.2.2. A Practical Theological Approach as an inductive Procedure

The empirical or operational scientific approach will be utilized to interpret gathered data to gain more reliable knowledge as a method of collective investigation. The researcher intends to reliably deepen the practical theological approach within the data gathering so that the people living with Albinism are not subjects in the research environment; however, they become the centre of the research and lifeline of the practical theology.

In agreement with the above descriptions, the qualitative method allows a researcher to engage with the community in which the study is made, experience them, and allow him/her the opportunity to interact with the participants by going to them during interviews.

Within the framework of the qualitative methodology, the conceptual theoretical frame to be employed will be of Nick Pollard's theoretical model of "positive deconstruction" defined in his book *Evangelism Made Slightly Less Difficult*. This is presented "as a process employed in helping people to deconstruct what they believe to look carefully at the belief and analyse."(1998: 44).

Pollard's process of positive deconstruction involves four elements identifying the underlying worldview, analysing it, affirming the elements of truth, which it contains, and finally discovering its errors (1998:48).

It is important to know the world has different types of people who believe in anything that will give them a meaning. It is advisable to help them not to look at the negative side of life, but help them to rise above anything that is prohibiting them to think positively.

Also concerning the study, the above theory will be employed to assist the families, the clergy, and communities to constructively develop new human paradigms of seeing persons with albinism as individual human beings, and secondly who are also created in His image, therefore, they are not fewer humans by their conditions. A new approach of deconstructing perceptions, misguided beliefs, and myth will be established.

This research is also going to use Gerkin's pastoral care that is found in his book, "*Introduction to Pastoral Care*" that introduces the theory that is shaped by the shepherding model in the historical Bible. Even though the shepherding image was originated as a metaphor that was used to describe leaders in the Ancient Israel history, it was never implemented as a designated role with the religious community, as were the priestly and prophetic roles.

Gerkin's methodology will assist to rebuild their lives anchored on Christ. This will help in liberating and enhancing the pastoral approach.

Gerkin identified the approach as; a prophetic, priestly, wisdom and shepherding model of caring ministry we inherit from the Israelite community are not to be sure. The only biblical images, which we pastors have to identify.

This will help in journeying with the troubled People with Albinism and their families, and to investigate the myths that encouraged their segregation. This dynamic will give a challenge to the church to get involved in caring for these people pastorally.

Gerkin further explains pastoral care as not for individual and their family alone, but also cares for the community and the tradition that gives them identity.

His pastoral care also indicates the shaping of the Christian community to suggest a dialogue that will bring an impact that will defuse cultural practice (1997:118).

The arrangement will encourage people to engage in asking questions that developed suspicions and the spread of unfounded rumours about Albinism.

A significant aspect was recorded in the Bible, where a leader was seen as a shepherd of a flock of God's people. Although this word originally came as a metaphor, this model was never recognized as a religious approach for pastoral care as the others, priests, and prophets. It only came into existence as a metaphor for Yahweh caring for the people of Israel. Psalm 23, is captured as relevant imagery as a good shepherd who leads people into the path of righteousness, which restores the soul of His people and holds the staff to protect them from the danger of the enemy. He has made a promise to cover them while they walk through the valley of death.

This is an indication that a good shepherd must be in a position to stand up and protect his/her flock by journeying with them and assure them availability. The neglected people living with Albinism and their families are wounded by culture and tradition, and they need a healer amongst them who will walk along with them in this journey of fear and discrimination.

This cannot be done by an ordinary human leader, but by guided people that have evidence of recorded shepherding records of accomplishment. Hence, the researcher identified the guidance of this method.

The researcher adopted the model to be a prophetic voice for the voiceless of Albinism. The caregiver needs to go into the world of the victims to understand them; they have to create a space in their space in order to bring hope. Gerkin also visited Jesus Christ's ministry where He practically applied His shepherding, prophetic, and priestly duties. He mentions, "Pastoral care of the sick, the bereaved and the dying also were included in the routine practices of the priest of the church"(1997:34).

A story of Martha and Mary, Jesus got into their frustrations after they lost their brother Lazarus. He was called, but came after several days, but upon His arrival, He instantly provided shepherding, priestly and prophetic voice, by assuring them that their brother will wake up. The Bible says "He wept". This is a sign of compassion; He occupied the space of frustration, grief, and hopelessness by being in the middle of their pain. He assured them life'.

Many have been gruesomely murdered in exchange for their body parts for muti purpose, the allusion about their mysterious disappearance. There above was attested by **Robert Banda**, a victim who works as a security guard. "He said that he was running his errands when he heard people arguing about the right monetary value for Him, he said 'as I walk towards the shop, some men shouted, and "There goes R10million."

People like Banda who have gone through that experience, need someone who will assure them that, it is not their fault that they are treated this way. Instead, there is help that will bring light to those who wrong them, someone who will not only show them but also walk with them to face their future with peace.



Gerkin further mentions that the first element in pastoral counselling emphasizes on psychodynamics and the inner life of a person as said by Carrol Wise." It is the communication of the *inner meaning* of gospel to persons that define the intentions of pastoral care at its best (ibid.10)

Good pastoral care embodies the gospel in a relationship, by speaking to the inner being of an individual (1997:88).

### **3.2.3. Descriptive study**

To, investigate the perceptions, misguided beliefs, and sub-cultural myths around the birth, fearing, and caring of a child with Albinism and to ponder on what support can be offered to them pastorally. To further deepen the descriptive role that pastoral community can play in journeying with people with Albinism.

### **3.3. Description of Environment of the study**

A field study is conducted in Rustenburg North West Province, in Geelhout Park, Tlhabane, and Phokeng, which are within the 10kilometres radius. A strict restriction has compelled the researcher to be broad about the exact location, to preserve confidentiality and the anonymity of the interviewees of a group of adults living with Albinism, males, and females, ages 20 and beyond, organized from the Association of People Living with Albinism in South Africa.

### **3.4. Clarification of Tentative Approach.**

The theory used in this study has not been completely tested in Practical Theology; it will therefore make prediction on what should happen. Scientific investigation has begun its investigations with a hypothesis that happen based on the ideas that was contained in the theory.

The word "hypothesis" is a noun, it is therefore an educated guess of what will happen; therefore, the outcome of the hypothesis statement is the outcome of the experiment and it will confirm the initial prediction.

For this research, the following observations will set an adjective to describe this theory.

### 3.4.1. Conceptualization.

According to Babbie, this is the process through which the researcher specifies what is meant when certain concepts are used within a particular context in the research environment. Giving a definite meaning to a concept by specifying one or more indicators of what is in the mind (2005:125).

Mouton further defines conceptualization as "participating one's study into a larger conceptual framework". (1996:118). For it is essential to relate one work to an existing body of hypothetical and practical knowledge.

In this research, this is to frame the empirically testable researched hypotheses, either by deriving them deductively from well-established theories or by basing them on observation of events in everyday life.

#### 3.4.1.1. Perception

For this study and the research, some conceptualized phenomena used will need to be redefined, to have a working definition for the purpose. This is how Makins *et al.* define perception as "the process by which an organism detects and interprets information from the external world employing sensory receptors"(1994:1156).

#### 3.4.1.2. Albino

Hornsby describes A person that is born with no pigmentation in the hair or skin, which are white, or eyes, which are pink (2015:34).

According to Oetting, Brilliant and King define "*albinism*" as a group of anomalies of melanin synthesis. It is characterized by a congenital inherited reduction or absence of melanin pigment in association with specific developmental changes in the visual pathway resulting from structural hypopigmentation. The word "*Albino*" means a white person; it is derived from the Latin word "*Albus*" meaning white. Since the 17<sup>th</sup> century, the word "*Albino*" has been used to describe living creatures with Albinism, having little or no colour in the skin, eyes, and hair. For humans, the term people living with Albinism is preferred by some because it emphasizes that

these are people like anybody else who lives with a special condition "*Albinism*" (Brocco, *et al* 2015:1150).

### 3.4.1.3. Care

The concept "care" according to Hornsby, is defined as "caution that one takes to avoid danger or mistakes, not taking any risks" (2015:216). The definition is inclusive of the description and the applicability of care as a feeling of worry and responsibility to deal with a situation; a process of caring and providing is needed for health and protection. Attention or a thought that one gives to something or someone to avoid mistakes or accidents or damage. The researcher understands care further as a noun meaning watchful attention; charge or supervision, or anything very concerned about.

### 3.4.1.4 Child

According to the electronic Merriam Webster Online Dictionary, a "**child**" is defined as an unborn or recently born person; dialect: a female infant; a young person especially between infancy and youth a play for both children and adults. A person not yet of age under the law she is still a child (Accessed 07 April 2019).

Whilst the Oxford Advanced Learners Dictionary defines it as," a young human being who is not yet an adult" (2015: 248).

However, a child can also be defined in description to associate him/her with a parent. Every person is a child to someone. Everyone is a child of God, our birthright belongs to a parent, and therefore, the word child can be used for describing a person who is associated with a parent.

### 3.4.1.5. Pastoral

The Webster's New Twentieth Century Dictionary of the English Language, Unabridged (1975), defines "*pastor*" as a Latin word meaning "*shepherd*". It is related to the Greek word "*pastus*", implying to feed or feeding.

A shepherd sees the nourishing, the welfare of the flock, and its subsequent growth. This is not a series of jobs that follow hierarchical levels or degrees of difficulty, responsibility, and status. The Oxford Advanced Learner's Dictionary defines "*pastoral*" as relating to the work of a priest

or teacher in giving help and advice on personal matters, not just those connected with religion or education (1986:614).

### **3.5. Creating an instrument**

Social research asking questions is the way of getting data for analysis and interpretation. Sometimes the questions are asked by an interviewer, sometimes the questions are written down and given to respondents for completion. In other cases, general guidelines help the researcher to frame and ask questions that will serve as an excellent instrument of valuables while avoiding mistakes that can result in misleading information. Therefore, a survey includes the use of a questionnaire. According to Babbie it is” an instrument specifically designed to elicit information that will be useful for analysis “(2005; 253).

While specific points to follow are more appropriate to a structured questionnaire than open-ended questions, questionnaires used in qualitative research in-depth interviewing, also underlie a logic valuable whenever we ask people questions to gather enough data. Therefore, descriptive measuring instrument scale was created, and expanded answers were used to measure existing perception raised in the questionnaire, which affects the Albinism stigma. **(QUESTIONNAIRE ATTACHED) ANNEXURE B**

#### **3.5.1. Sampling Methods**

Kumar stated that “sampling is done to create a small group from a population that is as similar as possible to the larger population and by studying the sample; it is possible to draw the valid conclusions about the larger group” (1999:177).

Whilst another definition of sampling is defined by Berndt and Petzer, as "the subset of the whole population which is investigated by a researcher and whose characteristics are generalized to the entire population"(2011:87).

On the one hand, Berndt and Petzer argue that there are two types of sampling and are probability and non-possibility sampling. For Malhotra "non-probability sampling is a subjective sampling approach that leads to a situation where all available sample people are

targeted and the non-probability sampling techniques include convenience, judgment, quota, and snowball sampling techniques" (2009:178).

However, Malhotra warned that non-possibilities sampling should be used with caution for two reasons.

1. During the process of non-possibility, sampling personal judgment is normally used in choosing the elements.
2. The sampling error is not assessed as a major drawback of non-possibility sampling because a statistical evaluation of the sampling might not be accurate.

The selection of the sample size for this study will follow the supervisor's recommendation to use 20 more research participants, ages 20 to 60.

(Bless and Higson –Smith) found that “when deciding on the size of the sample, the most suitable criterion to apply is one that ensures the sample sufficiently represents the populations: "sampling is a more accurate approach in terms of delivering information as compared to study the entire population (2000)

Both authors agree that the sample should represent the population of the area.

### **3.5.1.1. Interviews**

An interview is an alternative method of collecting survey data, rather than asking the respondent to read questionnaires and enter their answers. An interview can be by voice recording the respondent or face-to-face encounter.

In the researcher's opinion, the empirical research will be utilized for verification of different independent views; however, a small number of families with such children, churches, or religious groupings with such members will be requested to give their experiences from a semi-structured interview. The locations or areas that the research will be conducted will be around Rustenburg near Phokeng and surrounding villages. An empirical approach will be utilized to interpret gathered data to gain more reliable objective knowledge as a method of investigation

A sample of 20 co-researcher took part as voluntary participants. They range from the age of 20 to 45 from different backgrounds of life. The co-researcher did incur some expenses, as the researcher did travel to meet them at the neutral place, they felt comfortable. In some cases, the

researcher had to send a questionnaire by email and call the respondent to explain some questions and they repost it back. This was done because most respondents are from this area but work outside Phokeng in other towns and come at the end of the month. They answered the questionnaire according to the area of specifications

### **3.5.1.2. Information Gathering and Synthesis**

In this study, the researcher conducted an in-depth literature review to determine whether or the same study on the topic for pastoral support has been conducted to the people with Albinism, their families, and pastors. The literature will be the source of orientation for conducting this study. The researcher will determine whether the information could be applied in the pastoral context. The literature on pastoral support services to families with Albinism is not available.

Besides, the researcher designed an observational system consisting of questionnaires for interviews, which were completed by a sample of parents and family members who have been involved in the caring of people living with Albinism. Information gathered from these questionnaires and interviews was used to identify the problem that would serve as a guide in the formulation of a model for pastoral support service to Pastors, which will be the product to this study

### **3.5.1.3. Research instruments**

Data collection from research participants will be collected using Questionnaires as "Appendix B." "Questionnaires are defined as "a document containing Questions and or other types of items designed to solicit information to the appropriate analysis" (2005:253).

Self-completed the questionnaire will be distributed primarily amongst others by hand for observations and emails for this study

Kent described, "A research questionnaire as any document that is utilized to capture data that is generated by asking individual questions on the research phenomena"(2007)

Cooper and Schindler stated that "A good data gathering tool possesses three critical criteria: reliability, validity, and practicality. (2008:88)

The questionnaire for this study has a cover letter, (Appendix A) with instructions and information regarding confidentiality, anonymity, and voluntary participation. The researcher

will inform the research participants of the confidentiality, volunteerism, and anonymity of the data that is to be given, accentuating that participants did not have to indicate their names or identifying tags on the Questionnaires each time the survey will be completed

#### **3.5.1.4. Creation of research instruments**

Zikmund advised “A Questionnaire design is critical in making sure that the questions included in the questionnaire are relevant to the problem under study” (2003:45).

Malhotra stated, "A questionnaire with good layout has clear instructions, the adequate separation between questions and properly located answer spaces. (2009)

The questionnaire for this study was developed using the information collected from the literature review and the questionnaire currently self-administered and is written in English. The first part of the questionnaire is answering the participant ‘s biography question, gender, nationality, age, and marital status. The biographic questions variables are considered important for determining the validity of the research participants. The list of the questionnaire will be answered in detail to engage and capture the experience of the participants.

#### **3.5.1.5. Administration of research instruments**

Balvanes and Caputi revealed, "The administration of the questionnaire is a critical stage of the research as it determines how well and accurately the participants respond" (2001)

Maake and Nyanjaya emphasized this:" When gathering the data, the primary researcher listened to the co-researchers’ verbal and non-verbal messages because verbal language alone was incapable of expressing their inner feelings (2012).

The distribution of the questionnaire to those who will be communicated by emails will first proceed by a verbal briefing by the researcher to email the questionnaires to those who are reachable by emails. The participant will be asked to return the questionnaire within 5 days if possible. However, to avoid a situation where participants would not fulfil a deadline, a follow up email will be sent to remind them.

### **3.6. Data Analysis**

Bless and Higson-Smith described data analysis as “The process carried out by the researcher once the data has been collected and the purpose of data analysis is to enable the researcher to identify consistent patterns from data” (2000).

An analysis and comparison of the data were conducted in this study to find the solutions to the questions derived from the research problem and the objective of the research.

#### **3.6.1. Validity and Reliability**

##### **3.6.1.1. Validity**

Burns and Bush define validity as the accuracy of the measures and serves as an assessment of the exactness of the measurement relative to what exists" (2010).

Whereas Cooper and Schindler describe validity as the;" validity of measurement instrument in the extent to which the instrument measures what is intended to measure" (2003)

Two types of validity are internal validity that focuses on the exact measurement of the instrument and the external validity that concerns the generalization of the research outcomes that also gives us the three methods for establishing instrument validity as face validity, content, and construct validity. Though the ultimate validity of a measure can never be proven, the researcher may agree to their relative validity on the bases of those steps that give us the three methods for establishing instrument validity (Babbie, 2005:148).

##### **3.6.1.2. Face validity**

Rowley explained, "face validity as an extent to which a test subjectively viewed as covering the concept it signifies to measure" (2001).

Babbie further refers to "Face validity as the quality of an indicator that makes it seem a reasonable measure of some variables. That the frequency of church attendance is some indication of individual religiosity. (2005:148)

Therefore, it seems to make sense to conclude that the face validity of this study will be enhanced by the research supervisor who will evaluate whether the questionnaire is measuring what it needs to measure before distribution to the research participants. The supervisor will



assess the ability of the questionnaire to examine the challenges facing people living with Albinism from the perspective of the participant, facilitator, and content outcome

### **3.6.1.3. Content validity**

Babbie defines content as how much a measure covers the range of meanings included within the content (2005:149). Iacobucci and Churchill advised that: content validity assesses the content of the measurement to assure the adequacy of the instrument content” (2010). The researcher examines the previous literature on Albino sufferings, content outcome measures in addressing the challenges facing the implementation of the pastoral care method to ensure content validity.

### **3.6.1.4. Construct validity**

Mouton refers construct validity as "the measurement of know how much the researcher knows that the item included in the scale or questionnaire actually measures the construct that they are supposed to represent.” From the Mouton observation, construct validity will extent to which a scale, index or list of items measures the relevant construct and not something else. Whereas, Yins mentioned that: "construct validity refers to linking data collection questions and measures to research questions and propositions" (2003).

The research objectives were formulated first, followed by corresponding research questions linked to the study literature reviews to ensure construct validity.

### **3.6.1.4. Reliability**

Mouton cited Smith, that the key validity criterion for data collection is “reliability.” “It is the requirement that the application of a valid measuring instrument to different groups under different sets of circumstances that should lead to the same observation.” (1975; 58).

Who posed this question, "Will the same methods used by different researchers and/or different times produce the same results?"

Reliability refers to the fact that different research participants be tested with the same instrument at different times, should respond identically to the instrument. It is therefore, suggested by this definition that reliability demands consistency over time.

Brink and Wood also defined “reliability as the degree to which the results of research yield similar results when conducted by another researcher or the degree to which the research could consistently be duplicated to yield the same results” (2001).

Fink advised that "there are four kinds of reliability which are: stability, equivalence, homogeneity, and complicated reliability" (2003).

The research questionnaire of this study constitutes the kind of questions that measured the same construct to improve the consistency reliability as mentioned in the previous heading that the questionnaire will be pre-tested. 20 research participants from the target population and the information will be used to eliminate problems to assess whether the essential statement was included in the questionnaire for ensuring reliability and validity.

Reliability is required in researchers to compromise between to control and produce the highest degree of consistency in researches to reduce recurring errors and Hence Cooper and Schindler state that; "reliability measurements are retested" (2003).

#### **3.6.1.5. Elimination of bias**

The literature search aimed to include all relevant literature on the Care for Albinism measures, the content outcomes measures in addressing the challenges facing the implementation of a method of pastoral care given to eliminate the bias. The findings of the study are based on the perceptions of the research participants that will assist to eliminate the research bias. The research participants of this study will be chosen using probability methods techniques that will enhance the accommodating of the study findings of examining the challenges facing the parents of the children with Albinism from the perspective of ordinary parents and the outcome of the content that will assist to eliminate the research bias.

#### **3.6.1.6. Ethical consideration**

According to De Vos, ethical consideration serves as a standard and source upon which each research evaluates its conduct and guidelines are adopted in the personality of the researcher (2005).

The researcher must not complain at all about ethical thoughts relating to research studies.

***Permission to conduct the study:*** must be clear to the participant

***Informed consent:*** The research participants will be properly informed of the purpose of the study and responses of the study and responses to the questionnaires would be based on informed consent (*Appendix A*)

***Confidentiality and anonymity:*** the research participants are assured that neither their names nor their identity would not be disclosed. Responses provided by the research participants will be confidential to respect their rights to privacy and will only be used for this study.

***Respecting intellectual property.*** All the sources used in this research work must be duly approved,

### **3.7. Preliminary Conclusion.**

Summarily speaking this chapter presented the research methodology used for the study. Then the research design was outlined followed by the target population and sampling methods. The chapter has also given a detailed description and explanation for the research instrument adopted. This chapter also gave an in-depth description of the validity and reliability of the study. The various forms of elimination of bias and ethical considerations were also discussed. Chapter 4 takes the research through the findings of the study presented.

## CHAPTER 4

### ALBINISM

#### 4.1 Introduction

The chapter will concentrate on the types of Albinism within the biblical period and the 21<sup>st</sup> century. The characteristics of Albinism within a given context are different due to the settings where people living with Albinism are found. The methodology and models used to examine the study in Chapter two, that is, the literature reviewed will further be investigated to find the salient aspects of Albinism. It is to try to unpack the cultural understanding of Albinism in settings that nothing is said about the kind of skin pigmentation. The scientific worldview and the perspectives of lay people which many of them are the ones interviewed already.

#### 4.2. Albinism and Genetics in the Bible.

The Bible is known to be the first book to record the events related to the creation of man. The book of Genesis recorded the creation of man as one of those that GOD declared as good. Genesis recorded the two stories of creation that is, from Gen.1:27 and Gen 2:7, which specifically indicate the creation of man by God. It is therefore proper to try to find the origin of Albinism with those that were found in the Bible.

Levin Schneir in his article mentioned the relation between Albinism and some prominent figures like Noah and Laban in the Bible. He articulated the Ancient Biblical Jewish resources that suggested that Noah and Laban were born with Albinism. He mentioned that Noah was born with white skin, as white as snow, long hair and eyes that was transparent to the sun, in his research he explained that the findings from the Qumran Scrolls, that confirm Noah having a red hair, and he might have manifested the first mutation for Albinism (vol.1 No.12003. Retrieved 2020/09/6.).

Laban, which in Hebrew is 'Lavan', which is equal to white, was a brother to Rebekah and his nickname means White. Schneir used Rashi, an 11-century biblical commentator, who portrayed Laban as a wicked seeker after riches, passing over Isaiah's conclusion that "white signifies purity, innocence, and righteousness. Rashi could not conclude himself and deals with Laban's covetousness, but probably was called Laban for another reason, but there is another feature

supporting the diagnosis of albinism, a relevant observation concerning his older daughter Leah. She is alleged to have an unattractive ocular feature, which compelled Laban to trick Jacob to marry her. Her defects are noted as weak and dull eyes in Gen 29:17. A Hebrew word used is "rakot" meaning "soft or weak" and therefore suggested that she had a squint or trachoma. From the above information by Rashi, it might be that Leah had partial albinism that manifested in her pale blue eyes and photo-phobia-discomfort and nystagmus ceaseless trembling eyes in bright sunshine (Vol.31.no1.2003) (Retrieved 2020/09/06).

#### **4.3. Broader definitions and descriptions of Albinism.**

Some several definitions and descriptions are very much scientifically based on defining Albinism. Scientifically in the sense that it is medically based and it does not merge with any indigenous knowledge systems of the origins of Albinism. It will be imperative for the researcher to further investigate the broader cultural aspects that relate to birth.

Albinism is also said to originate from the word "albus" meaning white in Latin. It is a genetic disorder resulting in a decrease or absence of pigmentation in the hair, eyes, and skin ([www.derm.theclinic.com](http://www.derm.theclinic.com). Retrieved 2020/9/6).

The researcher in scrutinizing several works of literature at disposal of defining the concept Albinism observed that the best way to describe Albinism is only in a scientific approach and Du Bois in N.O.A.H (National Organization for Albinism, and Hypopigmentation), states is "*a genetic condition most often characterized by a lack of pigment in a person's hair, eyes, and skin.*" It is caused by inheriting a recessive gene from each parent and occurs in approximately one in 17000 people in the U.S.A and the world. According to Du Bois, there are no sources in the current document. While the condition is quite rare, one in seventy persons carries a recessive gene for a type of Albinism (2008:29).

Other authors have embarked on a narrow definition of Albinism, the meaning remains the same, and it is described as "a rare and non-contagious, genetically inherited condition present at birth" (A/HRC/24/57.retrieved 2017/8/31). In almost all types of Albinism, both parents must carry the

genes for it to be passed on, even if they do not have Albinism themselves. The condition is said to be found in both genders in all countries of the world, regardless of ethnicity

The physical features, the social structure, and superstitions beliefs system provides the foundation for further chauvinism on a social rejection of Albinism.

### **4.3.1. Types of Albinism**

#### **4.3.1.1. Oculocutaneous Albinism(OCA)**

Oculocutaneous Albinism is the most common form of Albinism and it exists in many different forms. OCA1 is caused by a genetic mutation involving the enzymes tyrosinase, which converts tyrosine into melanin. The first is referred to as OCA1a and is sometimes called "complete albinism" It is characterized by the body's inability to change the amino tyrosine into melanin. People with OCA1a have no pigment and have white hair, white skin light blue, grey, or violet eyes (2008:29).

The second kind is OCA1b, in which people develop some level of tyrosine's activity and detectable amounts of pigment and can even slightly tan. The amount of pigment varies in different people, but most doctors agree that people with OCA1b have some observable pigment by the age of two. Therefore, if a child shows no signs of freckles or darkening of his /her hair or eyelashes by the age of two, she /he has OCA1a.

#### **4.3.1.2. Ocular Albinism (OA)**

According to Du Bois, "ocular albinism", describes the inherited condition that differs from OCA in that, the eyes lack melanin pigment, but the skin and hair show normal or near-normal coloration. With ocular albinism, the colour of the eyes may vary from blue to green or even to brown, and sometimes darkens with age. However, the light shines back through the eye upon examination since the very little pigment is present in the retina (2008:30).

Du Bois explains that: a mother who carries the gene for ocular Albinism may have speckled pigmentation in the back of their eyes, but do not have the full syndrome of ocular albinism. The only major difference between OCA and OA is x-link inheritance. This means a boy with OA who has daughters will give each of his daughters a copy of his OA gene (2008:30). One parent

explains that he has two sons, but her second son was born with OA, she never knew that she carries the gene for ocular albinism, but she was told that she has 'albino' spots in the retina. However, nothing was explained further, she said she was told that she might have opted against raising a family due to ignorance about albinism.

#### **4.3.1.3. Hermansky-Pudlak Syndrome**

Hermansky-Pudlak Syndrome or HPS is a rare type of Albinism, it occurs roughly one in a million births in the general population. However, this type of Albinism is much more common in Puet Rico, where one out of 1800 people have HPS and one in twenty people carry the gene for HPS.

Du Bois explains that people with HPS have a common characteristic such as decreased visual acuity, involuntary eye movement, and varying degrees of hypopigmentation (2008:32).

HPS is said to be rare, in that case, a brief discussion of the implications of having this type of albinism is said to be very serious for those children affected. According to Du Bois; "People with HPS exhibit the characteristics common to most types of albinism, such as decreased visual acuity, involuntary eye movement and varying degrees of hypopigmentation" (2008:32)

Form the above information it is only clear and common that Albinism is a birth defect that comes through heredity. People with Albinism inherit the genes from both parents who carry those genes. It cannot be cured but can only be controlled by adjusting the way of life in taking precautionary measures to avoid the damage effects of the environment.

#### **4.4. Dynamics affecting Albinism.**

Albinism is visible because it involves the outside appearance of the body. In many cases people living with Albinism experience negative forces that weigh down their self-esteem. For an individual with Albinism, society can be so cruel. Some have cold-hearted attitudes and are judgmental towards them.

This can come forward as stigmatization, name-calling untruth misunderstanding about their condition. People with Albinism can develop cancer easily if they can be exposed to radiant sunrays. Their eyes also cannot be strong enough to handle too much light.

Those closely related to them always make a sacrifice of being there for them. In other cases, they have friends and they grew up with whoever accept them without any conditions.

#### **4.4.1. Dynamics during Biblical times.**

There are traces of Albinism in Ancient Biblical times whereby the Book of Enoch, recorded Noah as a person born with Albinism. Although the book was not recorded in the Bible but was also found to be hidden amongst the Dead Sea Scrolls at Qumran. ([www.blackhistoryinthebible.com](http://www.blackhistoryinthebible.com), retrieved 2020/9/15)

The following information was found to be recorded that;” *After a time my son Methuselah took a wife for his son Lamech. She became pregnant by him and brought forth a child, his flesh was as white as snow and red as rose, the hair of whose head was white like wool and long and whose eyes were beautiful. When he opened them, he illuminated the house like the sun, the whole house abounds with light, and he was taken from the hand of the midwife, opening his mouth, he spoke to the Lord of righteousness.*

*Then Lamech, his father was afraid of him and flying away came to his father Methuselah and said: I have begotten a son, unlike other children, he is not human, but resembling the offspring of the angel in heaven. Is different from ours, being altogether unlike to us”*

([www.blackhistoryinthebible.com](http://www.blackhistoryinthebible.com), retrieved 2020/9/15)

Although this can be a study for another time, it is evident that Noah has a white Albinism skin, it is clear that his skin looks different from other people, that even his father Lamech regarded him as an angel. The text proves that white skin was not common in human beings, that those with white skin were regarded as angels.

Russell Crowe (2014/4/3) from BBC also mentioned the same information and this can later be taken as another study ([www.bbc.com](http://www.bbc.com), retrieved 2020/9/15)

Noah as the first person with Albinism was treated differently, although there is no discrimination, but is the first step of being treated differently especially by his father.



#### **4.4.2. European and medical dynamics of Albinism**

Albinism is also common in Caucasians, and cancer is a common disease amongst them. The causes of mobility and mortality amongst them. The lesions that develop at a younger age may develop into an advanced stage of cancer in their lives.

With limited awareness of its genetic inheritance, this gives rise to numerous deep-rooted myths and superstitions ([www.ncbi.nlm.nih.gov](http://www.ncbi.nlm.nih.gov), retrieved /2020/9/15).

For example, it is believed that Albinism is linked to the conception during menstruation and this is culturally unacceptable or considered punishments from the gods for mistakes made by ancestors. This is socially entrenching discrimination and brings a negative impact on their quality of life. This brings them to mostly drop their studies and they later encounter difficulties in getting employments and getting married. Their families are also subjected to this discrimination, which leads to psychological distress.

#### **4.4.3. Asian and African cultures with albinism dynamics**

People living with Albinism look different because of the colour of their skin and hair. That is why in many communities they are being viewed as "people that are not us" (Atiemo, 2013; 134). This explains why people are being classified, and those who are the minority are always vulnerable because they are being unfairly treated. Haar explains that this 'otherness', which is often justifiable either through religion or secular, and this, disposed them to different treatments on the ground (2000:14).

Mistreatment against people living with Albinism globally is always deep-rooted by culture. Hence, this research is aimed to investigate those misguided beliefs and establish what can help them to be incorporated in the community.

#### **4.5. Cultural understanding of Albinism.**

Different cultures have their own ways of dealing with the subject of Albinism. In all the cases, people with Albinism are being mistreated because of their appearances. In the interviews conducted, everyone mentioned how culture has shaped their livelihood. However, culture has played influential benefits in influencing this behaviour, hence, Gielen, Draguns, and Fish

describe it as part of the environment that has been generated or created by human beings (2004:2).

From the beginning, culture has wrongly labelled people with Albinism because of the way they look; hence, everyone reacts differently when they first see these people. Albinism has been common; instead, culture chose its way of recognizing it.

For example, in Setswana culture, it is believed that marrying into a family, like marrying your cousin can cause Albinism, as family genes are the same. However, there is one advantage that the family understands the cause of Albinism, takes care, and supports the affected person. However, in culture, these people will like to suffer more unfairness and discrimination.

Name-calling and being ridiculed all the time and some instances they were beaten and avoided by their peers who would not even eat or play with them; some were avoided by their families who would not share food and clothing with their relatives (Lund.2001: 16).

In a recent case study in one of the incidents that happened while, the researcher was busy with the research; a particular incident caught the researcher's attention. The names are not going to be disclosed to protect the identity of the person. This is one of the case studies that made me realize that there are deductions when coming to Albinism.

### **Case Study:**

*The researcher came across is the self-defensive mode that other people with Albinism practice, whereby this happened in one of the retail shops in Rustenburg where two siblings with Albinism entered the retail store.*

*A sales person who happened to be having Albinism confronted them.*

*They asked for help in the store but instead of getting help, they were verbally attacked by one person with Albinism because they looked very different in the way they handled themselves.*

*In the confrontation, he asked them: "what are they using as a lotion? They told him even that they use medical insurance to obtain their treatment. This guy asked the two siblings if they affiliate with the Albinism Society of South Africa, and they said no:' and he said why?*

*They said because we are fine and did not see the need to become affiliates. And he said: you think you are better than us”*

*He started to throw heavy words on them, that the researcher assessed them only as a cry for help. "As I looked at this guy, he looked angry and frustrated. You could see the cry out for help in his eyes. His skin was dehydrated and had dark patches and the mouth had wounds. You could feel the frustration of saying, I need help, and you sound as if everything is normal" This guy attacks another person with Albinism because he looks different from Him, he had his frustrations, and the only way to deal with, was to attack this other person with Albinism.*

This made me realize that some visible deductions can be recognized in the world of Albinism, as much as they have the same equal rejection amongst themselves, some have violent behaviour towards others. The question may arise from the whole intentions of isolation. Is the organization aware of the struggle they go through, because, I managed to sit down with the man and ask him some question, and I realize that, as much as they belong to the organization; they do not get much attention. It is just a support group, but does not have an audible voice.

They go there to belong, hence when I asked him that. Am I allowed as an ordinary person to join the organization, he said, "no", you do not have Albinism, so you cannot be in our organization? I might be wrong, and this might need some further investigation but it looks like, they belong to support each other, but do not want the world to be inside their space. The support they give one another is not something to give life, but to increase the anger amongst them. If they can be able to attack one of them because they feel that he/she think she/he is important than them, it shows a lack of motivation and encouragement.

Some of those who belong to the Albinism Society of South Africa marry one another, have their activities alone, and to those who do not, suffer personal attacks from those who do.

There is more of a negative attitude in their circle of life. Lawrence describes an attitude as a "firmly held assumption or belief, usually learned in an emotional climate and therefore charged with strong affective components?" (1977:54).

This means that deep counselling is needed first because this is a behaviour that has been perpetuated by wrong assumptions.

#### 4.6. Conclusion.

Albinism like all other physical imperfection is the result of the first man that God created. Hence, their descriptions are the same in all cultures.

Their skin is sensitive to the sun; they all stand a chance of contracting skin cancer. The cultural misconception and myths have put them in a position of being discriminated against.

Albinism awareness has not been taken into consideration in all spheres of the world, looking at Lamech's reaction when he first saw Noah. This proves that the misunderstanding about Albinism has been there. With this reaction, it also brought about some questions about how they look.

This behaviour was expanded from generation to generation until it was decided that, they are special; therefore, they can bring some fortune to people.

The problem facing these people needs not just a word of mouth but also the action of those who have a voice to protect them. The only way to eradicate the cultural mishaps is to raise awareness even though there are no attacks.

An ongoing awareness can be able to teach people about the unjust behaviour that was introduced by the evil that was to represent culture.

## CHAPTER 5

### DATA ANALYSIS.

#### 5.1. Introduction

This chapter will present the analysis and interpretation of the research findings. The greater part of the interpretation is to talk to qualitative research as it has been identified to address the research style.

Babbie describes it as a qualitative analysis, which is a "non-numerical examination and interpretation of observations, to discover underlying meanings and patterns of relationships" (2005:387).

As much as Babbie describes a qualitative data analysis processing method in this manner Mouton further mentioned that; 'these methods were used in getting data ready for analysis; the collected data were coded by assigning symbols to answer (1996) so that responses can be put into limited names of categories.'

The researcher gathered data by doing in-depth interviews with parents, families, community members, identified as a neighbour, persons living with Albinism, and insight from pastors. The chapter will report on interviews, in verbatim, as the purpose is to provide the information from "people within the experience." Therefore, the story will remain in the area of participant's intellectual information. They will give an account of what is happening to the world of Albinism with the results of the analysis. The results of the analysis will be compared with the objectives to confirm if the objectives and the research question of the study were addressed.

The healing method will be in conjunction with the current two authors that are Gerkin with the shepherding model and Nick Pollard's narrative on positive deconstruction will be of paramount importance as far as pastoral care of people living with Albinism is concerned. The deconstruction process will encompass the social, pastoral, and spiritual elements that will be part of the Albinism care and community care approach.

### **5.1.1. Ethical Consideration**

The research considers ethical issues by taking care of the quality of the collected data and to guarantee the privacy of the participants. Personal data is kept anonymous for those who do not belong to the research group. The participants were requested to take part freely, by agreeing to answer the questionnaire by filling in the missing part of the forms. The researcher will give a lengthy report back of the interview she had. A registered Social Worker was supervising contact interviews. Some interviews were done in December, in the company of a Social worker, but most were done during a lockdown, therefore because of the restrictions of the lockdown by the government, the questions were sent to the participants through emails and WhatsApp chat and a social worker was called to observe the interviews. 35 questionnaires were sent, but 19 were returned. In others, there was no response. 9 of the questionnaires were sent by WhatsApp chat, so follow-up could be made and WhatsApp calls were used to conduct a virtual interview and the social worker was observing the interviews. The virtual interview gave a feeling of emotional encounter with the participants. The other 10 of the 26 questionnaires that were sent by emails were answered and returned.

### **5.1.2. Limitations of the Study**

The research must almost certainly face some limitations that may affect the direct conduction of the study. Time availability of participants was one of the limitations, whereby some participants could avail themselves as agreed, and others could not. Not all participants were positive. Some would pose some negative statements for them to be excluded due to their inference and ignorance, and they rejected the request. Furthermore, the sample size and approach of inquiry-based on the qualitative by nature limits the generalization of the study findings.

Having said that, the participants were recruited by identifying them and were called to make appointments. Before the interviews, the researcher explained to the participants what the research was about, and what it sought to achieve and explained the context of the study. All the interviews were conducted in English, at times clarity was needed, and the researcher paused to analyse the question for the participant to understand. All participants had at least basic education (grade12). The stories will be summarized based on the researcher's observation of a

non-verbal communication experience during the interview. The analysis of the gathered data will follow as per said stories. The stories will form part of the analysed data and findings. The stories from the pastors will help with the conclusion and recommendations.

The following categories were used in participation.

- a. 5 mothers as primary caregivers, who have raised a person living with Albinism.
- b. 4 Families who have raised children living with Albinism.
- c. 2 Neighbours who have been part of the families.
- d. 6 persons living with Albinism
- e. 2 pastors

The researcher needs to interview the family for they have experience within, their response from people when they first receive this child is important for this research. The mothers will give the insight of being a mother and raising a child living with Albinism. In an African culture ‘*go twe matlhaku go sha mabapi*’ in Sotho/Tswana translated as being neighbourliness’ *ngwana sejo wa tlhakanelwa*” in Sotho/Tswana **translated** as Mbiti said" it takes the whole village to raise a child.

Everyone has their own experience of life, they will tell their feeling better as they feel because, it is said that ‘*seso se monate se inngwaelwa ke mong was sona*’ in Sotho/Tswana meaning, expression in verbatim, "they have different personal encounters". Their encounter will give a different insight into the experience of people living with Albinism. The pastor's answer to this question will confirm the need for a pastoral training of pastor about the care of People Living with Albinism. The length of the interview took about 2 months probably because of the reluctance or procrastination by the interviewee.

The researcher had to send the questionnaires more than once, eventually after several follow-ups. The interview is voluntary, in some cases, the researcher had to supplement with data, as some people are unemployed and had no means of data. However, a minimal amount that is less than a hundred rand was provided for people that needed data. The researcher will not reveal the names of the interviewees but any other information will be given as authentic as all of them

gave it. Hence, a consent form was sent with the questionnaires that are recorded as 'Annexure A.' No interviews lasted more than five minutes.

### 5.1. 3. Interviews

For this research interview, a set of questions open-ended, unstructured and structured questions were prepared and drafted as in interview guide to administering the proceedings through oral or verbal communications and was prepared and presented to the participant.

According to Babbie, a questionnaire is a document containing questions and other types of an item designed to implore information appropriate for analysis (2005).

It is used as an instrument specifically designed to bring out information that will be useful for analyses.”

## 5.2. Presentation and Discussions

### 5.2.1 Interviews Report.

According to Mouton, a report represents the construction of the research process, this means that a report is written to present one's case as understandably and convincingly as possible (Mouton.1996:170)

**Annexure B** is prepared questions, which will be tabled at the end of this chapter. The questions will also be tabled bellow to make the communication a bit easy.

The first answers are from the mothers as the primary caregivers, the research refers to them as primary caregivers because they gave birth, and they are the first to lay eyes and hands on the child. Five questions were tabled.

As follows. **Question 3** and **4** have also followed up questions labelled as **a, b, c** as follows

- 1. How many of your children have Albinism*
- 2. Can you tell me about your journey with Albinism?*



3. a. *Share with me, what came into your mind when you were holding and looking at the baby?*

. b. *What information can you share about Albinism?*

c. *What troubles you about their lives?*

4. A. *How do feel when people say negative comments about them?*

b. *At what point do you need to be relieved from caring?*

c. *What responses do you have about their killings?*

5. *What role can the church play in their lives?*

c. *What responses do have about their killings?*

5. *What role can the church play in their lives and of those who Care for them?*

**Question 3.** Has followed up questions labelled as **a, b, c**

(a. *Share with me, what came into your mind when you holding and looking at the baby.*

b. *What information can you share about Albinism?*

c. *What troubles you about their lives?)*

And 4 has also followed up questions labelled as **a, b, c** as follows

. a. *How do feel when people say negative comments about them?*

b. *At what point do you need to be relieved from caring?*

c. *What responses do you have about their killings?*

Participants must answer all questions, except for question 1 and 3, which will not be directed to participant's **c, d,** and **e** Participants' **e** had their questions.

## 5.2.1. Profiles of participants

### Mothers Profile

The first participant the researcher interviewed was a 27-year-old mother residing in Geelhoutpark, section 6. She lives with her two children living with Albinism, a boy and a girl, she has a small business to augment the family finances, her husband works at the mine in the Northern Cape, he lives there in the family unit compounds, and she only visits him during the school holidays. She chose to come to my place for the interviews as she said "she wanted to be free to talk" Her husband never said anything about the way the children look like and he never goes anywhere with them, but the mother-in-law always visits them and she is not comfortable to leave her children with her. Because of what the members of the family including the mother have said about how she is the one who contributed towards the colour of the children's skin colour. She has a bright skin colour with greenish eyes.

### Interviews

Below follows, the methods used to display the way questions were asked. The question was done in detail on all the first participants in each category, and then all other participant's stories were done in summary form for other participants.

#### Research Questions

*1. How many of your children have Albinism?*

#### Participants

**Answer. One**

*2. a). Can you tell me about your journey with Albinism?*

It was easy because we had a known history my mother gave me support helps me to cope by taking care of the child. Although we never had a talk with my mother about them, the mother-in-law blamed me, for the colour of these children in the family. I got all the support from my own family

*b. What information can you share about Albinism?*

**Answer.** "It has been a hectic experience because. I had some questions and did not know whom to ask. Both children were, a boy and a girl, were born with the condition at the local hospital, but not much was said about the way they look. I became shocked in my silence, I did not even ask anything, but like I said" I got my support from my mother."

*c. What troubles you about their lives?*

**Answer."** My baby had white skin with yellow hair and greenish eyes. She as Albinism that she inherited from the family." I am not sure if they will ever be safe or live a normal life"

*4. A. How do feel when people say negative comments about them?*

**Participants."**I feel helpless and keep quiet because people call them names that humiliate them".

*b. At what point do you need to be relieved from caring?*

**Participants** "If there can be an open voice to teach about Albinism. I think there must be a platform where people can be told about Albinism and their care."

*c. What responses do have about their killings?*

**Participant"**-I feel scared as my child is not safe".

*5. What role can the church play in their lives and of those who Care for them?*

**Participants** "I a member of the St John Apostolic church; the children were not yet baptized as their church can only recognize adult baptism, but, when I am at the church people stare at them, and I stop going to church with them, but no one asked where they are.

The above table represents the type of questions that were asked to the participants. On the other participants, the researcher will summarize the responses of the participants.

## **Profile**

The second person is a 53-year-old mother. She is married and has only one son with Albinism. She is a working mother, and resides in Tlhabane West, the husband is also working, and the

husband has never said anything about the child, he never goes anywhere with the child. The researcher went to their home for an interview.

### **The interview**

On asking her about her journey with Albinism, she explained that it has not been an easy journey, because she never expects to have a child that is different from her and her husband. She feels very disturbed because of the attention she gets from the people she meets. She said everyone wants to give her an advice on how they assumed this child must be raised. She said she feels that she is too overwhelmed about all the attention she gets from the people. Asking her "what worries most about the child, she said, "I wonder if he will ever have a normal life as any other person. She says people want her to feel better by saying that the children are the same as any person, but she feels that it is deeper than what the people are saying. However, she has learned to cope with all the comments. She is a member of a Lutheran church and goes to church but leaves the child at home because she is always disturbed by the comments after church.

### **Profile**

A third participant is a 55-year-old mother; she lives in Phokeng, she and the husband have a son who has Albinism. The husband is retired and the son is older and not working. He stays with the family; fortunately, he is getting the government grants. He has an eight-year-old son, the mother is not staying with them as he is not married to the mother, and the mother does not have Albinism. He is no longer in a relationship with the mother, but he has an opportunity to be visited by the child.

### **Interview**

On asking her about her journey with a Child with Albinism, she explains that; it was not an easy life; she said she loves her child not to let anyone hurt him. Asking her about what troubles her about her child, she said" I know that he is being called names, but I cannot protect him because people say whatever they want. "She said recently she sent him to their neighbour to give them a message, but the neighbour slammed the door on his face saying, "He must never set his foot on his yard as he brings curses in his yard." It brought a shock to them because their son grew up in

the neighbourhood and they have been neighbours for decades. The son has stopped going to church but has not explained why.

### **Profile**

A fourth participant is a 37 years old mother who is divorced and has four children. The three children ages 15, 12, and 10 years are from the previous marriage. The last child has Albinism, is from the current marriage. They live with a husband who is 40 years old; their home is in the township of Tlhabane. The child is only one year old.

### **Interview**

She says she is still learning how to take care of the child. She has learned that the child needs extra medical care because his skin is sensitive to the sun. He said the first time he saw the child he became shocked and asked the doctor, why the child is different. She said the doctor explained to her and it was fortunate because the father was around to witness and hear. Asking what troubles, her about her child, she said, " I will not be able to protect him from the stigma. That makes her very scared and she is now being overprotective to her son. However, so far, she never experiences any sort of negative talk about him. Being the child of a pastor herself, she grew up in the church and has never seen a person with Albinism in the church.

#### **5.2.1.2 Families Profile**

The first family consists of a father who is 50, working in the town of Rustenburg, a mother is 39 years old and works in town as well and three children. All the children attend the local school and they travel by taxi to go to the same school. The setting was at their home in Geelhout Park, a middle-class suburb in Rustenburg. The family has three children of the ages of 18, 15, and 8 of which the first two have Albinism and the third one is dark in complexion.

### **Interview**

When responding to a question of "share your journey with Albinism," they responded, but the mother was the one responding in most time. The husband did not have anything to say but in the report that the mother is giving, he was a bit distance with the show of a concern to all what

the wife was saying., she mentioned that their journey has not been easy after having the children who came as a surprise not in a negative way.

Just a shock as everyone expects to have a child looking like a father or a mother. The parents had to adjust in many ways, as the children needed so much attention. Having to deal with stigma was their fear. However, they treated them as normal as possible to build character on them. Because they said, one day they have to be independent, they must be used to face the world on their own with its harsh realities. If they knew that their life would be in danger, they will be more careful, but their life can only be good if they are cautious.

### **Profile**

The second family consisted of a mother who is 40 years. She works as a nurse in the local clinic, a grandmother is 75 years old on pension, she was an educator in primary school, and five other children but only one has Albinism. They live in Chaneng village outside Rustenburg the first four children are born “normal “that is how they describe the others who have their mother’s complexion, only the last born has Albinism. Two of the children are at the universities, the other two are still at high school, and the last with Albinism is at the lower grade.

### **Interview**

The grandmother explained that, in the family, there have been people with Albinism. So this one was not a surprise, and the family experienced humiliation in many cases. She explains that although the child was well known in the community, there was always a stigma that he carries. Because he would one-day come, back crying that other children have called him “*lekgowa*” (a white person). People will say things as he will not die but just disappear without a trace. According to the grandmother, it brought humiliation to the family, but they loved the child and always comforted him. She said when this one comes; they took it as a blessing. When asked what troubles her about their life, she said; their creams are expensive, for their skin to look beautiful, they must use a certain skin product that cannot be found in any retail store. Their eyes are too sensitive to the sun; they need some ultraviolet eyeglasses. When they lack personal care, they lose confidence and people mock them. At least that is their experience. She said that she has been a member of the church, but the church has been silent about their experience.

## **Profile**

The third family is from Kroondal. Both the mother and father are 45 years and have two children. The whole family has Albinism. They have their own home. A girl and a boy have inherited their parent's condition. The father works for the mine, and the mother works for the government. The family had not much to say, except to say that, "it was not a shock for us to have children like us. According to them, they met at a special school together and got married.

## **Interview**

When the researcher asked them about their journey with Albinism, they explained that, life has not been that easy because people are always staring at them. They say the children always tease them about how they look. The husband explains that if I could drive, I would travel with the family in a car, and the children would not hear all the comments that are said about them when they go into the taxi. I asked about what troubles them most. They explained that their safety and those of their children, the wife explained that, with all this news about the killing, her husband works shifts at the mines. She always has this fear that he might be kidnapped. The husband says; we are like this, and people are saying things that will not make us change, and we cannot force them to keep quiet. There is not much to say about Albinism, except when someone is killed. When a person with Albinism dies, people come to witness that, the person is dead, because of the rumours that we do not die but disappear.

The answers about the negative thoughts, explain, "It is something that is beyond our control. People grew having misconceptions about people with Albinism. They must be educated against such.

The fourth family is consisting of a mother and father and a son. They live together at "Lemenong". The father is working, but the mother is a homemaker. They live in their own home. The daughter has Albinism; she goes to the local crèche. The family tries to have a normal life and the incident of the killing has never happened around, but with all the rumours, they think that people will have the perception of starting to kidnap and kill them. That raises a concern to them. The family explains that last year the wife was hijacked while taking the child to the crèche. The rumours started to circulate that; the highjacking happened because they

wanted the child. That created fear amongst everyone in the community, but the child was found abundant in the same car somewhere. The mother explained that: since that time, we learnt that the child's life is in danger, that the child can be kidnapped anytime. "I asked about what troubled them about their lives. They mentioned the comments, which people are saying and how they need to be on the alert and guide against the hijackers.

When asked about the support of the church during and after the high jack, they explained that nothing happened and it was not even mentioned at the church.

### 5.2.1.3. Neighbours

In the African culture, neighbours are important, and there is an idiomatic expression that says in **Setswana**" *matlhaku go sha mabapi*. (Translated as, when one is affected, then neighbours are also affected). It is common that black people who stay in the same neighbourhood look out for each other. Their children grow up together, play, and sometimes share meals. When one neighbour struggles to survive, the other would look out for them, that is what Timothy Murithi describes as;" being generous, hospitable, friendly, caring, and compassionate. Sharing what they have. It also means that my humanity is caught up, is inextricably bound up, in theirs. We belong in a bundle of life (2006).

We say, "A person is a person through other people" (*in Xhosa Ubuntu umntu ngmntu ngabanye abantu and in Zulu Umuntu ngumuntu ngabanye abantu*). I am human because I belong, I participate, and I share. A person with *Ubuntu* is open and available to others, affirming of others, does not feel threatened that others are able and good, for he or she has a proper self-assurance that comes with knowing that he or she belongs in a greater whole and is diminished when others are humiliated or diminished when others are tortured or oppressed, or treated as if they were less than who they are.

Therefore, it was important to interview neighbours who witnessed the growth of these children. The interview took place in their home. The researcher chose neighbours randomly from all different participants' areas to get the views from a people who did not know each other.



#### 5.2.1.4. Profiles of neighbours

The neighbour or a community member is a father, who is 70 years of age; he lives with the wife and teenage grandchildren, in Phokeng. He is the neighbour of one of the participants. He first showed resistance to talking with me, but later agreed after a bit of persuasion from the wife.

#### Interview

As discussed above not all questions were asked to him. Only 3b.

#### Research Questions

*1. A. What information can you share about Albinism?*

**Participant:** ‘I grew up people with Albinism being called “*maswafe*”. They were not popular when we grew up. However, I know that it has to do with a heredity condition. Because we did not have them in the family, and here in Phokeng, they were not many of them, I never have much interest in them. What I grew up knowing is that they do not die but disappear.

*b. What troubles you about their lives?*

**Participant:** “I always felt for their parents, because of what people were saying about them. The discrimination, but like I said, I never paid much attention to their lives”

*c. How do you feel when people say negative thoughts about them?*

**Participant:** "As I said, I don't know what to say about it, but feel for their families.

*e). What response do you have about their killings?*

**Participant:** “It is much sad how people behave in this world. I hope the government can bring the worst punishment to those who kill them.

*2. What role can the church play in caring for these people and their families?*

**Participant:** I have never heard the church saying anything, even about this killing. I think the church must start saying something to help to pursue the government

The same questions were asked to the second neighbour.

The second neighbor was a 65 years old man and his wife. They live next to the family; the family is no longer living in the neighborhood. The family is 8 years in that neighborhood.

When answering the above questions, he said that "he knows that people living with Albinism, have been known as "*maswafe*." He grew up knowing that they bring a "curse" to the family. He grew up knowing that, if you see them you must spit on the ground so that your offspring should not be albinos. He said that nothing troubles him about them because he cannot have a relationship with them. About their killing, he said they are not that popular in their area; however, they disappear, and that is why they are not that many in the area. He said the church has never said anything about them because their parents hide them, so they are not known to the church.

The researcher asked him if one of his children can have one, what is he going to do? He, "said only God knows". The wife did not want to say anything or answer any question.

The researcher experienced calmness in the granddad's words; he knew all the actions but made it not his business. He passively answered the questions.

#### **5.2.1.5. Profiles of People living with Albinism**

##### **Profiles**

The people living with Albinism are the centre of this research; the researcher has invited the people with Albinism to give their story as well. The researcher indicated in the introduction above that, some of the responses will be quoted verbatim which will assist in letting the researcher not lose the gravity of the pain or personal experience of the participant.

##### **Profile of a person living with Albinism**

The first participant was a 42-year-old, who does not have any children and is staying with the family in Tlhabane West, the mother, father, and the niece. He is not working now and grew up with the challenge of having a poor vision. He managed to get his senior certificate, but could not proceed to tertiary due to some personnel challenge that comes with living with Albinism.

## Interview

### Research Questions and Answers from the Participants

*1. How many in your family have Albinism?*

**Participants:** 'I am the only one'

*2. Can you kindly share your journey with Albinism?*

**Participants:** 'As a person living with Albinism, my journey has had its challenges. The first was dealing with oneself (internal issues), acknowledging that one lives with Albinism and that nothing is going to change. Secondly dealing with external factors, people's misconceptions, myths, attitudes towards people with Albinism. Etc.

*b. What information can you share about Albinism?*

**Participants:** Albinism is only skin deep, nothing more. Other than that, the visual impairment factor that is usually also prevalent in varying degrees- there are no other differences between us as a person living with Albinism and those that do not.

*c. What troubles you about their lives?*

**Participants:** The prejudice or in some instances patronizing, that we are subjected to regularly.

*2. How do you feel when people share negative thoughts about them?*

**Participants:** It upsets me because I know that it all stems from ignorance.

*b. At what point do you need to be relieved from being cared for?*

**Participants:** I do not require intensive care; I just need to be me and be loved as the person created in God's image.

*c. What do you think about the killing of people living with Albinism?*

**Participants:** The killing of any human being –irrespective of their condition-is inhumane and satanic. It is incumbent upon us as people living with Albinism, and governments concerned to embark on rigorous awareness campaigns to dispel the myths surrounding albinism. Secondly, law enforcement and the justice system must act swiftly against the perpetrators of these heinous crimes

*4. What role can the church or caregivers play in this journey?*

**Participants:** The church can help by liaising with an organization at the ground level (schools, NGO, etc) through awareness campaigns, celebrate national and international days (days for people with Albinism month) furthermore, the church leaders and preachers can in cooperate issues of Albinism in their sermons. (Moses. Despite his speech impediment, the Lord used him greatly)

### **My observation**

My observation of this participant is that he is aware of his condition and has built his character around who embraces him. He is aware of all the negative energy that other people bring to him. He has made peace that, he will always be bullied, and there are things that he cannot change, but people need to be educated about Albinism. From his interview, he showed independence, because in his interview as he says. “I do not require intensive care, I just need to be me, be loved as a person created in God's image. The feeling of discrimination is overwhelming him. His plea is that people with Albinism need to be respected within their space. The self-understanding made the participant cope with all the challenges he met.

Wimberly (2000) mentioned, “Human beings also develop a positive self-understanding by adapting and identifying with positive narratives and roles through which they can orient their lives” (Wimberly.2000:24).

### **5.2.1.6. Profile**

The second participant has Albinism, is a 40-year-old male, he is unemployed and living with a family. He is not married and comes from the siblings of five. They are two with his sister who has Albinism in the family; the other sibling has dark skin. They grew up in rural area of Taung village in North West but they moved to Rustenburg with the family. He has no child of his own. He went to school and has the only senior certificate.

### **Interview**

On asking him about the journey with Albinism, he mentioned that he experienced extreme criticism as he grew in the village. He was called names like ‘**lekgowa**’ a Sotho-Tswana for describing a white person. He further mentioned that his mother showed support as he grew up, though he always came to complain about the negative comments from the street, his mother

never said anything. Asking him about the father, he said his sister and himself do not have any relationship with his father. He said people with Albinism are people that differ from others with colour, and just needs to be respected. He says he struggles with blindness, and that makes life very difficult for him and his sister, as they cannot find proper work. He said when people make negative comments; I just keep quiet and ignore them. He said, 'I cannot run away from the fact that I am Albinism. I cannot change how I look, but I can only deal with what is inside me.

He further said that he feels relieved to have moved to the urban area, the killings mostly happen in the rural area, but it does not mean that he is safe. However, the news about the killings is upsetting. He says that the church can play a prophetic role by raising the concern to the people about Albinism; they have access to the people of all cultures and stature.

### **My observations.**

I observed that the participant experienced the same problem as the first one. The difference is that the first participant has more confidence than this second one. That is because the first one has financial stability and he is employed. Therefore, all these negative energies destroy his self-confidence. He does not work, and that makes him have low self-esteem.

### **5.2.1.7. Profile**

The third and fourth participants were interviewed at the same time. They were two female friends who both lost their mothers. One is 27 and the other is 25 years old. They were both living with relatives who were not very friendly to them. The other one does not have a relationship with the father, and the other does not know her father. One has a nine-year-old child and she is working in the government department. The other does not have a child and she is not working.

### **Interviews**

Both of the participants spoke about their journey with Albinism, they both say they have experienced being called names because of the way they look. The stares they always have to come across. As they grow up, they realized that the need to teach people about Albinism was urgent.

What troubles them is how people react when they see us. The myths are still there in the villages when we visit. People see us as people who are lucky and have supernatural intelligence. About their feeling about the negative comments, they answered, well, everyone is entitled to their own opinion but people are clueless about Albinism, and most react with different gestures.

The care that we need is just love, and to be respected like other human beings. On the issue of the killings, it all comes back to a lack of knowledge by the society. People are clouded by these beliefs and judgments, but cruelty is what they practice. The church needs to speak out from the perspective of being near the people of all stature. There is a need to reach out to people to give the teachings.

### **My observations**

From both of these participants, there is the same type of treatment from the people, because they are always together, they share the same experiences and find comfort in each other. They seem to have shut the world out and live their lives in isolation. They built a wall against the world and have shut everyone out. They both have no mothers and have decided to protect each other. They take every day as it comes and do not expect anyone to come to their defence.

Amongst other people that were interviewed were the pastors. They were asked the same questions and the interviews are as follows:

#### **5.2.1.8. Research Questions for Pastors**

*1. Can you give your views about the church and the care of people living with Albinism?*

**Response from the 1<sup>st</sup> pastor.** "I honestly have not paid much attention to the issue of the church and Albinism. The church is too silent as compared to homosexuality and prostitution. We are not giving attention to them. I only engage with them because I feel pity for them.

**Response from the 2<sup>nd</sup> pastor:** "The Church has never been actively involved in dealing with people living with Albinism. It has just taken them like ordinary congregants and has never reached out to their care and pain. The social construct of the church has always been to embrace different people with the same blanket and weave them together without considering their background, dynamics, and fears. Just like single parents, transgender people, people living with

Albinism have always been taken as by the way people or non-citizens for the church." My view is that the church is a closed book for people living with Albinism and not willing to open up to their care and agony.

*2. What response can you give about myths that people with Albinism do not die but disappears*

**Response from the 1<sup>st</sup> pastor.** "I heard that when I was growing up but came to realize that, it is not true. My brother had a friend with Albinism, but he later passed on, he attended his funeral. I did not attend the funeral.

**Response from the 2<sup>nd</sup> pastor:** "I grew up knowing that myth and having believed it. However, after ordination and being fully involved in ministry, I had an opportunity to attend the funeral of a person living with Albinism. It was well attended by the villagers of that particular area. Before the funeral service could commence, there is a tradition to ask the people to come and see the corpse and people went in their numbers. The myth then was demythologized in that respect.

*3. In your service as a pastor has the church responded to the allegations?*

**Response from the 1<sup>st</sup> pastor.** "Not at all ". The church is silent.

**Response from the 2<sup>nd</sup> pastor:** A distant church cannot respond to the allegations as it is in a faith and hope intensive care unit (ICU) as an institution. The myths that persons with Albinism do not die but disappears were never responded to by the church, as it has never engaged itself in their lives and care.

*4. Have you ever buried or attend the funeral of a person with Albinism?*

**Response from the 1<sup>st</sup> pastor:** "I have not attended the funeral of any person with Albinism

**Response from the 2<sup>nd</sup> pastor:** "Yes, I have attended, as I said in the other question I responded to." As a minister has just conducted one and the member was about 77 years of age." It was just a normal funeral; however, the attendance was extremely beyond the normal funeral attendances.

*5. Do you think people with Albinism need to be given special care?*

**Response from the 1<sup>st</sup> pastor:** "The church has the responsibility to take care of God's people, regardless of their form of background. Nevertheless, if I am given that task, I do not know how as to where to begin, as I have never engaged. I need to start by learning them.

**Response from the 2<sup>nd</sup> pastor:** "A church is like a spiritual hospital, the spiritually down and wounded come to it for healing, counselling, and care. As such, I hold a strong view that the church has to care for them as a beacon of hope when the society and community are ill-treating and rejecting them. It is not necessarily special care, however, is to realize that they also carry the same likeness and image of God. They are just like people living with disabilities. Theirs is rather on a pigmentation level and not mentally or otherwise. As such, the church should reconstruct itself, in such a manner that talks to the "theology of God's image". The voice of the church must be relevant to the marginalized and "likeness wounded"

#### **My observations.**

From my observation of the pastors, there is a gap that the church has from the people with Albinism. The gap is created by either ignorance or lack of knowledge about how to care for people with Albinism. As one pastor said:

*As such, I hold a strong view that the church has to care for them as a beacon of hope when the society and community are ill-treating and rejecting them.*

In his statement, the church cannot be mute after hearing the struggle the people with Albinism are going through.

### **5.3. Interpretations of Discussions and Findings**

From these research findings, the participants were of different ages and gender. The findings indicated that the minority were youth. The participants were between the age of 27 and 70; those who took more part were from the age of 45-70. It is shocking to hear that people can be treated this way. Investigating the myths from different generations indicates that every generation followed that same trend of discriminating against them; most of them had particular names that they use to call them. They all treat them differently from the others to an extent of not even showing any sensitivity about how they feel.



The findings indicated that the majority of the active participants who took part in this study were matured, indicating that they have more knowledge about Albinism and their social challenges. People living with Albinism and their families have been living in hurt for many generations.

This study's data collection process involves the participants on a different level of education, occupation, and profession some are working, and some are not, so the study is meant to gain useful information in this experience. The characteristics of this participant and occupation were not much of the request. A social worker, being a person having more experience, and having a deeper understanding of the trauma was relevant to observe.

The research deals with issues of Albinism; it assessed the distribution of people living with Albinism who participated in this study. The study had targeted to get the inner feeling and coping strategies employed by those living with Albinism in responding to societal attitudes and perceptions. Hence, the researcher included them in this research and some who are not.

### **5.3.1. Albinism in the family**

Some families agreed to know Albinism, but some did not have however, there was only knowledge. The findings from both non-P.LWA identified several needs as follows:

As much as they need Health education on how to take care of themselves, to prevent cancer by getting protective clothing, security protection, mainstreaming education. They also need spiritual care.

On societal attitudes and beliefs, the result has indicated that some respondents had a negative attitude toward these people, by looking at them:

As disabled and abnormal people.

As misfortune in the family

As a resource for wealth

However, the majority of the participants had positive attitudes towards them. They view them as a normal human being. However, existing negative attitude shows that PWLA makes them not safe in their social life and their well-being in the community. This statement is supported by one participant who said: *“I am a member of the St John Apostolic church; the children were not yet*

*baptized as their church can only recognize adult baptism, but when I am at the church people stare at them and I stopped going to church with them, and no one has ever asked where are they”.*

This reflected that P.L.W.A suffer much from the rejection by the community and their right have been denied. Literature in so many researches confirm the abusive states in which P.L.W.A are living. In so many inner voices, the participant indicated that there is a problem within the community of Albinism.

The result reflected that there is a need for strategy and collective effort with the church to ensure that knowledge and education on Albinism is promoted. Because some people believe that-

Albinism is a curse.

Are spirits from the dead person in the family?

The mixture of a person with Albinism’s body part is thought to bring good luck and prosperity.

There is a poor understanding of Albinism; society is the link to discrimination and social exclusion. There is a need for collective strategy and effort by the church to ensure knowledge and education.

That P.L.W tend to withdraw from social gatherings to avoid being noticed.

Due to socially rooted discrimination, the equality of life of P.L.W.A is being challenged.

In light of the traditional myth about Albinism’s existence, they are being subjected to a great deal of stigma. Stereotype attitude gives P.L.W.A, a death sentencing.

They are being called names like “Mlungu” a Nguni word for describing a white person

“**Zeruzeru**” – ghost or gesture

“**Leswafe**” I am not sure what to call it in English, but it is a loose translation by the Sotho-Tswana speaking people when they refer to an Albino, which is derogatory in a way as they are correctly called people living with Albinism.

The question may arise that, God created all human beings, and He said everything is good. *Now, what went wrong? Where did we lose them as people to call them all these names? Where did they lose that image of God?*

The lack of correct knowledge on Albinism resulted in myths and the discrimination of P.L.W.A. In line with stakeholders that are, raising awareness only when there is an incidence.

### **5.3.2. Discussions**

The result of the discussions that reveal that some participants were negative about Albinism. Such findings are a very painful experience for P.L.W.A; they need a physical expression of love and care. There are several myths address in the discussion that bring a concern to anyone who read them. The myth about them disappearing.

The question may arise if they disappear into the bush and die:

Does someone raise a concern about their disappearance?

What about the family, does the family keep quiet about their disappearance?

Superstition, are the "normal", this attitudes and beliefs need to be addressed.

It is difficult for them to find an identity on the issue of disability.

In the line with the comments of the two pastors, it is clear that care is needed from the church.

## **6. Preliminary Conclusion**

People living with Albinism are struggling to fit amongst the societies they living amongst. It is an old traditional myth that was supposed to stop by those they live with including the church. There has never a proof that validates the rumours that their parts are good for making people rich nor being cursed when you meet them on the street. In the interview with members of the community, the myth has been there for many generations, and has led to this saying” they don’t die but disappear. (Which still needs to be researched)

For various reasons, Albinism can be seen as a unique condition. However, uniqueness has led them to be isolated from the social realm.

These attitudes include a lack of understanding of the fear of the unknown, prejudice based on their appearance as one of the participants mentioned it. The findings showed that their health and education is a concern, and their spiritual care must be taken into consideration. The church needs to stand up and take up an assignment of being a prophetic instrument to the people with Albinism.



## CHAPTER 6

### 6. METHOD OF HEALING

#### 6.1. Introduction.

From the beginning, the point has been made that a church is starting to find a pastoral method to deal with people living with Albinism. Hence the introduction of caring for these people. From the responses made by the pastors, it became evident that people are not popular in the church community.

The initial problem with this research is 'care' which is initially found in Biblical tradition and was developed in the Christian tradition. For this reason alone, pastors need to understand how moral problems present themselves and have to present them as they are. It is, therefore, important to help them to develop themselves to help in caring for these people.

In this chapter, the researcher will discuss how pastoral care can change the way people are being treated. The researcher will introduce how Nick Pollard's theory of positive deconstruction which can influence positive energy to the church community they belong to bring dignity to people with Albinism and their family. Charles Gerkin's pastoral care theory will help with the caring method that pastors will use to journey with them by entering into their space to bring healing to their long silent sufferings.

#### 6.1.1 Reality of Ignorance and the frustration that is caused by 'normal'

From the interviews, the pastors mentioned that they have never personally engaged with the people living with Albinism. Yet radios and all media platforms have said so much about their treatment. They face the frustrations alone and have taken it upon them that, they are being mistreated and they are alone in this journey. They face the frustrations alone and have resolved to keep quiet and die alone because according to one participant, he always told his mother about the humiliation they get from the people. The mother never even answered him. It cannot be clear because the mother knew that it was expected of her to give her child the support he deserved. I see ignorance in these whole situations, which is brought by a lack of knowledge to engage on the subject. It is having been there for ages and it will not go away until someone does something about it. The inability to question the practice of traditional myths has decreased them to the level of their humiliation. Even though they are frustrated, they are pushed to

accommodate the "normal" that is said by the people who do not want to get involved. In one interview on SABC, the youth made it clear that he cannot control how people respond when they saw him, but he chose to remain honest to himself.

### **6.1.2. Using 'normal' to cover a lack of interest in knowledge**

Lack of knowledge to engage in the issue concerning Albinism makes all parties concerned helpless. In some instances, it may look like ignorance. It has become apparent that they are very aware of the negative force that is brought about by these people. Their failure to interrogate the practice of traditional myths has cut them to a level of paralysis.

This can be sensed from the old man's hostile behaviour expressed in the interview when he said"

*"I never pay attention to their livelihood; I grew up knowing that they do not die but disappear."*

It is very evident that he also added frustrations, which have made people angry and frustrated, as no one has ever been curious in finding out the truth about this. The belief was that "whatever is unknown should remain there. "The rearing of people in the matters affecting people living with Albinism is normal in their family.

Hence my argument that people in the middle of their lives, those who care for them, are hurt and are dying in silence. This statement proves this: from this mother that:

*It has been a hectic experience because. I had some questions and did not know whom to ask. Both children, a boy and a girl, were born with the condition at the local hospital, but not much was said about the way they look. I became shocked in my silence, I did not even ask anything, but like I said, "I got my support from my mother."*

### **6.1.3 Forcing 'normal' to ignore the truth,**

Several participants in the interview had indicated the normality of Albinism, and that people must take upon themselves to understand, they have their struggle. As much as rumours are there about their existence, respect should be the order of the day.

As much as they commit, and try to live a normal life with these people, this brings more questions than answers: If God the creator has created everyone in His image, why other people like people with Albinism have to live their lives having to explain their looks.

Wimberly explained that: "God's story and God's history is what makes human being's stories meaningful, and when God's story, or the big story, impacts our individual and our church stories, our lives become meaningful. It is God's story and God's ultimate goal for participating in history that gives God's work and our calling to vocation meaning" (Wimberly 2011: 45).

Every human being's existence has God's Divine expression to support His mission. Hence, human beings have different colours, structures, and appearances to impact individual life, which should be passed on to our church lives; this is to support God's statement of creation. Therefore, it is important for everyone, not to question, and interrogates this mission. Albinism is more identifiable because of the bright colour of their hair, skin, and eyes; therefore, questioning a genetic coding is questioning the work of God. We all have an image to be identified with. This is strengthened by our culture, even though the environments can influence culture. Where myths influence and can dictate culture to take another direction.

Different African scholars have debated that African identity as an image can be dictated by culture. Africans are normally described as black people, although there is white cultured in the mist, African culture is visibly practiced because of our historical relationship with the practice of recognizing our ancestors. When a child is born with a certain form of different image, the family looks for the answers from the lineage or fore-parents. This is what is called "connecting the dot." This what Mbiti describes as individual identity, which he describes as the communal identity that surpasses the individual identity (Accessed 25 April 2018).

## **6.2. Using pastoral care to change the attitude of "Normal"**

According to Patton pastoral care is a ministry of Christian community that takes place through remembering God's action for us, remembering who we are as God's people, and hearing and remembering those to whom we minister (1993).

Therefore, pastoral care is working with people to experience the power of the living God in the land they live in. giving hope to people that God's love is sufficient to anyone even those who are

marginalized. If the pastor can get involved in bringing people with Albinism close to them, space will be created for care.

### **6.2.1 Pastoral care in the “Normal”**

“Normal “is the word that is commonly used by people to ignore what People with Albinism are going through. When I was talking to one Pastor about people’s reaction amongst these people, he ignorantly said, “those people do not have a problem; they are living “normal ‘life they don’t have a problem. I see nothing wrong in how people interact with them.

### **6.2.2. Pastoral approach to bring awareness**

In one of the interviews, one participant said:

*I have never heard the church saying anything, even about this killing. I think the church must start saying something to help to pursue the government.*

A pastor has a good chance of using their place of worship to spread awareness about Albinism.

The problem may be the method is not yet clear, as they never had interests in attending to their special needs

### **6.2.3. Bringing them back to society.**

According to Wimberly relational refugees, need a positive relationship with one or more individuals whose attitudes they can internalize. (2000:23) their way of living and rehearsing their own ways of living

Wimberly believes that; human beings learn to live in a healthy, whole manner by seeing such practices demonstrated by others they trust, imitating their living patterns and rehearsing them. Some people living with Albinism have never been part of the healthy environment in their community, at the least to be shown how to be actively involved in the community. In this case, trust is one problem that they have to learn to practice. In all stories, it is mentioned that they live in fear of being ill-treated.

We all need to be surrounded by people who have a positive attitude towards us. Because such an attitude becomes the base of a personal self-image. People feel loved if people who become interested in what they are going through are surrounding them.



Wimberly, took John Wesley's theology which brings to bear on our faith tradition current and contemporary knowledge and wisdom emerging out of pastoral practice. This is a therapeutic and healing theology of Salvation that speaks to issues of shame. Shame is understood as pulling yourself from the community and this result in a person thinking that they are being unloved. (2011:21)

#### **6.2.4. Mentoring.**

One thing that can bring people to make their lives meaningful is to claim the dignity from God. The process that can only through mentoring. Societal conversations are very powerful and can always shape the way we see ourselves. It is not easy for one to survive negative conversation within our community, hence bring God in our lives bring dignity.

Wimberly describes mentoring as a process of ordering experience, giving priority to certain stories, scenes, role, and attitudes" (Wimberly .2000:34).

This means that a mentor must have a relationship with the person he/she is mentoring. People with Albinism have been isolated by culture, for them to be mentored back into the community; they need a person they can trust. In this case, a pastor needs to come closer to them to listen to their hardships and mentor them into the community. This is what Wimberly calls: strategic intervention. Wimberly says mentoring involves helping the relational refugee feel at home in the world emotionally, spiritually, relationally, and cognitively (Wimberly 2000:57).

Every person needs someone to emulate, this can serve as a measuring stick of life in the sense that, one will know that he is on the right track of life. African culture has viewed Albinism as a non-human that contributed to their brutal treatment by some members of the community. It is a pastor's prerogative to reach out and avail himself or herself to everyone so that those who felt to be victims should go for help. Therefore, if pastors themselves are not equipped, they cannot be confident to say, they are there to help. Pastors need to serve the community they are serving with equal consciousness. Ministerial formation programs should be employed to correct the cultural biases and prepare them to be observer with care.

### 6.3. Constructing a theory of care for pastors.

Given all the above statements, it has been discovered that pastoral practices and care need attention to resolve society's lack of knowledge. The researcher, therefore, realized that there is a serious need for a paradigm shift within the structure of the church. A method of care needs to develop and caregivers must be encouraged to increase their praxis to fit in with the needs of their congregants. The task that now waits for pastoral care is what Masango has articulated in his article that: “God called caregivers to love and they are capable of loving because God loved them first (1 John 4:19). Through the caregiver's love for others, he or she will bring hope to the hopeless. However, this love and hope can never be sourced from within the caregiver's self.” (Vol.68. January 2012. Retrieved June 2020)

The researcher mentioned in chapter 1, aims and objectives that the aim of this research is to correct misguided beliefs and sub-cultural myths about the birth, nurturing, and caring of people with Albinism and further consideration of the pastoral care methods that assist in this matter. It is therefore proper to help caregivers to journey with people with Albinism and their families.

Within the theoretical framework to be employed, the researcher identified Nick's pollard theoretical model of "*positive deconstructions*" as explained in his "*Evangelism Made Slightly Less Difficult*" this journeying with the wounded that will help them to positively deconstruct the bad things they have experienced.

As much as the researcher chose the abovementioned theories, it was also relevant to test on other scholar's views on pastoral care. Carrie Dochrings post-modern Approach on pastoral care describes pastoral care and their characteristics. She prefers the word "pastor" as an adjective, which is found in a Biblical text and Christian tradition. Therefore, Pastoral Care takes much form depending upon the historical and global context in which it is offered. It comes with supportive care, which is a spiritual presence that comes alongside people in an ongoing way such as visitation at a strategic moment such as baptism and premarital counselling (2015:1)

Dochrings explains, "Supportive care sustains people through the losses and gains of live transitions, especially as they began a new chapter in their stories. In this journey, a pastoral and spiritual journey is a two-part process that begins with trust and then moves into the creation of life-giving Theology.

In agreeing with Dochrings, when there is trust between the care seeker and the caregiver, a relationship will be built and the process will have some good results. Because, when the care seeker trusts that care giver will respect what is unique about their religious beliefs, values and spiritual practices can begin. However, this depends on the readiness of the pastor. Below follows the usage of the Pollard method of “Positive Deconstruction and Gerkin to develop a method of training to the pastor to help to bring the pastor to the life of People living with Albinism.

### **6.3.1. Nick Pollard’s Positive Deconstruction**

Nick Pollard's story about his ministry as he tried to talk to people about Jesus indicates that, they chose to speak about anything but refused to listen to his story about Jesus. That is why he ended up bring a positive mind that will help to bring positive energy to live right.

In this book, “*Evangelism Made Slightly Less Difficult*” Nick Pollard shows how to break through the barrier of disinterest. He shows why Jesus can and should make a difference for the people you know. He shows how you can interest them in learning more about Jesus. Along the way, Pollard examines why people think the way they do and provides help for better understanding and challenging non-Christian worldviews. He also answers sceptics’ tough questions, offers practical methods for explaining the gospel, and gives suggestions for leading others in their first steps to faith in Christ.

Evangelism may never be easy. Nick Pollard's imaginative approach, infectious enthusiasm, and field-tested advice will make it slightly less difficult. He introduces the method of approach that will bring positivity in a hopeless person and that method guides him to this reach to reach his goal. Being positive, bring dealing with challenges as they come and not accepting things that are not in line with what you believe and stand for. A positive energy attracts good life that can influence our surroundings.

The process of *positive deconstruction* is described as the method that will help people to deconstruct positively or take part in what they believe in this journeying with the damaged souls to help them think positively (1997:44).

By applying this theory in this study, the researcher has identified withdrawal behaviour in the community of Albinism and those who care for them. There seems to be a sense of fear of the

unknown from the people who care for them. The negative attitude that is brought by the community they live within, that is perpetuated by cultural myths, brings discomfort to the community. The cited participants' answers have identified a lack of pastoral leadership.

People living with Albinism have been unfairly treated by culture, it is therefore necessary to have someone with spiritual experience to walk along with in order to confess shame and externalize it. Wimberly says; in the process of confessing shame, one externalizes it, that is, shame is acknowledged by allowing oneself to be aware of its existence, but detaches the self from it by means of placing it outside the self (1999:75).

Wimberly and Pollard share the same idea on looking beyond hurt and leaving it behind. It is important that the people living with Albinism move away from self-pity and be helped to claim their dignity. However, they need a hand to carry them through this journey.

Dochrings describes the process as compassion that is stepping respectfully and compassionately into another's narrative world with the metaphor of hospitality. Embodying compassionate respect and entering into another person's religious or spiritual world not knowing when will encounter sacred images (2015: iii). A sacred space is private and cannot be invaded except being invited by the owner. In this cases people living with Albinism has had their lives being separated from the ordinary public life. Because they have never shared their space with anyone, they need someone who can walk with them and teach them to be open and accept company in lives.

Few participants have highlighted some points about the no involvement of pastor in their lives. Therefore, pastors need to practice compassion to enter their space, as there is already a resistance built between the parties.

The real problem is rectifying what culture has damaged; there is a need to create a therapeutic space that will permit them to create their own healing.

### **6.3.2. Charles Gerkin's. Shepherding Model**

And Charles Gerkin' shepherding model. Whereby a pastor is being identified as shepherd. A title owned by David of the Bible; he was a shepherd of his father's flock. A shepherd is patient

and caring; he protects and understand the flock that it is tending. In his book; Introduction to Pastoral Care, he identified four models of caring identified as follows:

A pastor as a shepherd of the flock

A pastor as a mediator and a Reconciler

A pastor as a Realistic leader

A Pastor as a Priest, prophet and wise guide.

### **A. Pastor as a Priest, prophet and wise guide.**

“We need to carry with us the balance the Old Testament Israelite ancestors struggled to achieve among the functions of pastoral leaders as priests, as a prophet, and as the wise guides of the people (1997:79).

Being a pastor gives you an authority to exercise a spiritual and prophetic voice to protect the vulnerable. When wrong activity is practiced amongst the community, we have to stand against it to implement fairness and equal justice for those who live around. To be the voice of the voiceless.

### **A Pastor as shepherd of the flock.**

Gerkin portrayed Jesus as a good Shepherd of the flock (John.10:14). The one who has “Authority” over life. This image displays a powerful person who can give up life for His people (1997:80).

Except for David who was one of the ancient people mentioned as a shepherd and ancestor to Jesus, both David and Jesus displayed that being a shepherd; they laid their lives for those that where are under their protection.

### **A pastor as a mediator and a Reconciler**

“**Under** the pressure of persecutions, and threat by the secular authority, the pastor’s role as a reconciler in many cases becomes authoritarian and arbitrary” (1997:81).

A pastor displays a powerful image in African culture. This culture dictates the pastor to be a neutral person who should not take sides in any matter that is brought before him/her. In this

regard, a pastor represents a person who should be compassionate about the people she/he works amongst.

### **A pastor as a Realistic leader.**

“Some care can only be given the power of deep connection with communal meanings by way of corporate participation in the symbolic acts of receiving bread and wine, the laying of hands, and the administration of the water of baptism’ (1997:82).

Our comfort comes from sharing the same body that we believe to give life and strength. A personal interaction of a pastor with those he/she serves is important as it displays equality to the community of the church and surrounding. A personal link has to be established between the church and Albinism by these theories.

Bishop Sphuka in his interview said:” we need to educate people about Albinism in our school and sermons. Noting that everybody is created in the likeness of God, and we need to acknowledge and protect them.” (Mindfulnessworkshop.29. August 2019).

The above statement from Bishop Sphuka in emphasizes a lack of knowledge about Albinism, by the community at large, and pastors are at the most in the right position to reach out. It is evident that the identity of a pastor is to empower members using the high office of authority. Therefore, pastors are in the ministry of caring not to decide to listen to some biased information.

According to Gerkin, “every office has its own role, and it is not independent of God. This is very clear that God expects pastors to work as a mouthpiece for the frustrated. He uses different offices to teach His word and will, that is why the word pastor can be translated as a shepherd of the sheep (1997: 79).

With the injustices surrounding People living with Albinism, a pastor is needed to act and support their emotional needs. With the divine authority, he/she must be prepared to answer difficult question with the authority from God. Pastors need to walk with those who seem helpless, to move them away from shame. The shame that Wimberly describes, as “being alienated from the community which produces a sense of being unloved (2011:21).

For so many outcries about the killings of these people and for pastors not responding, it is a sign of either not knowing what to do or choosing not to get involved.

## **7. Preliminary Conclusion**

The response on pastors' interviews gave an indication that pastoral care giving in the field of Albinism is not there. The applied Pollard and Gerkin's methods proved the point that there is a lot to be done in the field of Albinism and pastoral care.

In the next chapter will be the research findings challenges, recommendations and conclusion.

## CHAPTER. 7

### 7. Recommendations

From the beginning, it was discussed that church has not done enough if not nothing to provide a pastoral service to most including people living with Albinism. Hence the introduction of this caring topic for a child with Albinism: A pastoral Challenge.

From the researcher's point of view, the word "child has been used as a collective name to those who are under a care of someone. From the responses made by the pastors. It became evident that people living with Albinism are not that popular within church. Those who are there are being regarded as ordinary people who are there and have a "normal life, however this type of attitude is destroying the reputation of the ignorance that is been practiced. "Normal" as been said by pastors is ignorance that can course frustration', it can also display a lack of knowledge, therefore lack of interest, and this can ultimately minimize the truth.

In view of all that has been discovered about pastoral care practices in the church, it has come to the researcher's attention that, a paradigm shift within the church needs to be visited and care givers should be encouraged to expand their praxis in order to match with the church community 's needs. The story of Gobakwang and other who are suffering the same fate, give more insight of the problem of this these people. Like those who took part in the research, a gap needed to be filled with regard to caring for the people with Albinism.

As indicated in the research aims that, a suitable theory should be developed, in order for them to care for those who need to be taken care of.

The word "care" was initially found in Biblical tradition and was developed in Christian tradition. For this reason alone, pastors need to understand how morally are obligated they are to present them as they are to provide care in the church community, it is therefore important to help them to develop themselves in order to help in caring for these people.

This chapter, will discuss how pastoral care, using two theories, that the one by Charles Gerkin, which is identified as a shepherding theory, that will help to develop the model that will to equip pastors in journeying with those who are vulnerable. Pastors can preach awareness, about



Albinism and that can influence positive behaviours about Albinism to society, in mentoring and healing.

The researcher will also explore Nick Pollard positive deconstruction, which will also influence positive energy to those, affected to change their mind settings and encouraging Jesus positive mind in dealing with un-favoured realm of life. As much as the researcher chose to use the abovementioned theories, it was also relented to check on others scholars' views on pastoral care. Carrie Dochrings post-modern Approach on pastoral care describe pastoral care and their characteristics. She refers the word pastor as an adjective, which is found in a Biblical text and Christian tradition.

From the interviews, the pastors mentioned that they have never personally engaged with the people living with Albinism. Yet radios and all media platforms have said so much about their treatment. They face the frustrations alone and have taken it upon themselves that, they are being mistreated and they are alone in this journey. They face the frustrations alone and have resolved to keep quiet and die alone because according to one participant, he always told his mother about the humiliation they get from the people. The mother never even answered him. It cannot be clear because the mother knew that it was expected and even if she responds, how often she responds as this will was an ongoing dilemma.

I see ignorance in these whole situations that is brought by a lack of knowledge to engage on the subject.

It is having been there for ages and it will not go away until someone does something about it. The inability to question the practice of traditional myths has decreased them to the level of their paralysis. Even though they are frustrated, they are pushed to accommodate the "normal" that is said by the people who do not want to get involved. In one interview on SAB.C, this young man made it clear that he cannot control how people respond when they saw him, but he chose to remain honest to himself.

United Nations has declared June 13 as an international day of Albinism Awareness day. In Malawi, they urged the government to join the rest of the world in marking the day as raising awareness. Because lack of knowledge to engage on the issue of Albinism make all parties concerned guilty. The U.N treated Albinism as something that needs attention, hence this awareness. It is an international day, but not many countries raise awareness about, because an awareness cannot be raised only in one day. This has to take much more than a day. In some instances, it may seem like ignorance. It has become apparent that the church is aware of this negative force; however, they do not use the day to condemn the practice of traditional myths that have cut them to a level of paralysis.

This can be sensed from the old man's hostile behaviour expressed in the interview when he said"

*"I never pay attention to their livelihood; I grew up knowing that they do not die but disappear"*

It is very evident that there are also added frustrations that have made people angry and frustrated, as no one has ever been curious in finding out the truth about this. The belief was that "whatever is unknown should remain there." The rearing of people in the matters affecting people living with Albinism is normal in their family.

Hence my argument that people in the middle of their lives, those who care for them, are hurt and are dying in silence. This statement from this mother proves it:

*It has been a hectic experience because. I had some questions and did not know whom to ask. Both children, a boy and a girl, were born with the condition at the local hospital, but not much was said about the way they look. I became shocked in my silence, I did not even ask anything, but like I said" I got my support from my mother."*

Several participants in this interview had indicated the normality of Albinism, and that people must take upon themselves to understand, they have their struggle, as much as rumours are there about their existence, respect should be the order of the day.

As much as they commit to try to live a normal life with these people, this brings more questions than answers: If God the creator has created everyone in His image, why other people like people with Albinism have to live their lives having to explain their looks.

Wimberly explained that: "God's story and God's history is what makes human being's stories meaningful, and when God's story, or the big story, impacts our individual and our church stories, our lives become meaningful. It is God's story and God's ultimate goal for participating in history that gives God's work and our calling to vocation meaning (Wimberly 2011: 45)."

Every human being's existence has God's Divine expression to support His mission. Hence, human beings have different colours, structures, and appearances to impact individual life, which should be passed on to our church lives; this is to support God's statement of creation. Therefore, it is important for everyone, not to question, and interrogate this mission. Albinism is more identifiable because of the bright colour of their hair, skin, and eyes; therefore, questioning a genetic coding is questioning the work of God. We all have an image to be identified with; this is strengthened by our culture, even though the environments can influence culture, where myths influence and can dictate culture to take another direction.

Different African scholars have debated that African identity as an image can be dictated by culture. Africans are normally described as black people, although there is white cultured in the mist, African culture is visibly practiced because of our historical relationship with the practice of recognizing our ancestors. When a child is born with a certain form of different image, the family looks for the answers from the lineage or fore-parents. This is what is called "connecting the dot." This what Mbiti describe as individual identity, which he describes as the communal identity that surpasses the individual identity (Accessed 25 April 2018).

According to Patton pastoral care is a ministry of Christian community that takes place through remembering God's action for us, remembering who we are as God's people, and hearing and remembering those to whom we minister (Patton: 1993).

Therefore, pastoral care is working with people to experience the power of the living God in the land they live in, giving hope to people that God's love is sufficient to anyone even those who are marginalized. If a pastor can get involved in bringing people with Albinism close to them, space will be created for care.

Wimberly introduces 'mentoring,' and he said, "Worthy mentors, skilled mentors, and compassionate mentors are needed to enable relational refugees to return home. Mentors with character and compassion can enable relational refugees to find a new story, scene, roles, and

attitudes to replace the negative stories and experience that are the underlying causes of their alienation."(2000:35).

I agree with Wimberly, that people with Albinism have been alienated by the society, and this has made them isolate themselves and build their environment that might be the cause of what people say, "They don't die but disappears." If this is the truth, then it proves the point that they isolate themselves to a point of not being seen again and ultimately is forgotten. Therefore, they need a trusting person who will understand their world or learn their world, not judge them.

"Normal "is the word that is commonly used by people to ignore what People with Albinism are going through. When I was talking to one Pastor about people's reaction amongst these people, he ignorantly said," those people they do not have a problem; they are living "normal "life they don't have a problem. I see nothing wrong with how people interact with them.

According to Wimberly, "Pastoral counselling can assist in reintegrating relational refugees into nurturing communities" (2000:25) that the techniques and concern counselling are important resources for the process of healing. People living with Albinism and their families are hurt by what was prescribed by culture.

"For the pastor involved in the day-to-day relationships with persons at all levels of social life, at least two observational capacities are of crucial importance. The art of listening involves more than simply hearing the words that people say, being attentive to the emotional communication that accompanies the words" (1997: 91).

Gerkin puts a pastor in a position to isolate him/herself from the emotional attachment and be a good listener, but giving attention to the detail of what a person is saying and walk along a relationship that is formed by attentive listening will allow the pastor to explore their intentions in caring. People living with Albinism have never had an opportunity to be attended to except in case of medical care. For them to have a relationship with someone outside can bring a sense of relief to their bottled life. A pastor as a shepherd must get into their space so that trust should be built, and introduce the conversation about care. Gerkin regards this as pastoral care of those in special need.

The church has never restricted its ministry to professionals; the mission of the church is the task of all its members. Therefore, pastoral counselling should be helping someone through conversation when one is entering conversation deliberately as a Christian and does not mean the conversation is limited to religious matters, nor needs to be a Christian. It means that counselling becomes pastoral when you and the other person are aware that the approach consciously as a Christian.

There are many approaches of counselling, whereby behaviour therapy should form part of. Jay Adams, represent more consecutive behaviour whereby he picked up that people 's behaviour is secondary and they can improve when person act responsibly. However, his approach is being criticized for leaving out the emotional side of a personality, about which the Bible has much to say and can encourage the manipulation of individual to bury their emotions in which could lead to a worse situation. The approach should encourage someone freedom to make their own choice.

Paton described pastoral care as the Theological conviction that human care and community are possible because we are held in (1993).

Many people with Albinism have been brutally murdered in exchange for money. It is so scary to hear those that have come across the situation. In one of the interviews, one participant said:

*I have never heard the church saying anything, even about this killing. I think the church must start saying something to help to pursue the government.*

A pastor has a good chance of using their place of worship to spread awareness about Albinism.

The problem may be the method is not yet clear, as they never had interests in attending to their special needs. Beside Gherkin's, Taylor also has an approach that can be practical, that tries to see the situation as it is in the context to the relevant situation. In his book "*Tend my sheep*", He is not from Africa but he is very concerned that people should think that culture is recognized and the western culture does not know. He gives wider range of healing. (Study guide 19:30-31)

According to Wimberly relational refugees, need a positive relationship with one or more individuals whose attitudes they can internalize (Wimberly .2000:23).

We all need to be surrounded by people who have a positive attitude towards us because such an attitude becomes the base of a personal self-image. People feel needed if people who become interested in what they are going through are surrounding them.

People assume that the People with Albinism are doing well in their space, but one participant mention that, *I have my problem of dealing with the way I look, and then I also have to be subject to people whom I meet and call me names."*

The above statement gives an indicates the emotional trauma that these people are experiencing. A voice comes from their inner being of being neglected by the community they live in.

Every person needs someone to emulate, this can serve as a measuring stick of life in the sense that, one will know that he is on the right track of life. African culture has viewed Albinism as a non-human that contributed to their brutal treatment by some members of the community. It is a pastor's prerogative to reach out and avail himself or herself to everyone so that those who felt to be victims should go for help. Therefore, if pastors themselves are not equipped, they cannot be confident to say, they are there to help. Pastors need to serve the community they are serving with equal consciousness. Ministerial formation programs should be employed to remove the cultural biases and prepare them to be caretakers.

In view of all the above statements, it has been discovered that pastoral practices and care needs an attention to resolve the society's lack of knowledge. The researcher therefore realized that there is a serious need for a paradigm shifts within the structure of the church. A method of care needs to develop and caregiver must be encouraged to increase their praxis to fit in with the needs of their congregants. The task that now waits for pastoral care is what Masango has articulated in his article that: "God called caregivers to love and they are capable of loving because God loved them first (1 John 4:19). Through the caregiver's love for others, he or she will bring hope to the hopeless. However, this love and hope can never be sourced from within the caregiver's self" vol.68. January 2012. Retrieved June 2020)

The objectives of this research were to investigate the caring element that is not visible to children with Albinism and the family as this not a condition of their choice to be born like that. The misguided beliefs and sub cultural myths are spread at birth, nurturing and caring and further

consider on the pastoral care methods that assist in this matter. It is therefore proper to help caregivers to journey with people with Albinism and their families.

The research affirms a lack of care from the side of the church. It has never come to a point where the church has got into a mission on adjusting to their needs. Apart from the two pastors that were interviewed, several pastors were interviewed in order to determine the knowledge that they have with this subject. It has come to the attention that all pastors have shown no knowledge of how to interact with people with Albinism. Most gave passive answers that, these people look fine, they don't look frustrated.

As a result, the researcher identified Nick Pollard theory of "*positive deconstructions*" as explained in his "*Evangelism made slightly less*" will give a theory to pastors to journey with the wounded, this will also help them to create platform to help them to come closer into their world and learn about the bad things they have experienced.

The data collected during this study has established the following sufficiency facts that people with Albinism and the families have been unfairly treated. The behaviour was encouraged by the fact that people around them assumed that it is normal to call the names that are not showing any respect of their existence. They suffered silently and as one participant stated that in that interview.

Though those that comes from a better background seems to have a better life, those who comes from the poor background suffer the most. Nevertheless, the fact is; they suffer the same fate of name-calling, and the names are the same in both black and white culture. As stated by an old man that we grew up knowing that, "Maswafe 'don't die but disappears, I have never seen a grave for people living with Albinism, this is evident that if the church cannot take an initiative on getting to equip themselves with the knowledge of pastorally involving themselves in this issue, the matter can be more dangerous than it is now.

The research has made me realize that, pastor do not pay attention to the fact that, the need to voice out to stop the brutal treatment of the people living with Albinism. Moreover, this happens because not many are exposed to them, but that does not give them the reason to not be involve in taking care of them. Generally, not all pastors are exposed to pastoral care, in many Seminaries; pastoral care is taken automatically as being mention in the Bible.

However, it is clear that not everyone is a pastor, in the African Methodist Episcopal Church, not everyone is addressed as pastors. Nevertheless, those who have charges. Those who do not have charges are called “Reverends or ministers simply because they may be doing ministry in a different department. Women who give birth to children living with Albinism goes through a traumatic experience of having to be exposed to emotional abuse. In the past, there were no teachings about genetic disorders. Those who gave birth without going to the hospitals had to be given false information in order to accept the child. Some had to be told that their children brought curses in the family. They go through the experience until the child is big enough to carry the comments themselves. Then the child has to go through the same experience and sometimes ended up being killed. This is a global phenomenon, some of the cases of their attack was never reported and this coursed the increase of their brutal attacks

It is therefore to note that not all of them are exposed to being a mentor or to work closely to the members of the church unless they work with those who have charges and then will have a personal encounter with members of the congregation. The following recommendation has been suggested by this research:

- a) An advocacy tool to raise an awareness about their condition and care need to be raised in the church as the church carries more weight of teaching about human dignity and the principle that the Bible teaches about the image that man carries in the face of the world.
- b) That a pastoral care to People living with Albinism be part of the training to the pastors. My encounter with those pastors I interviewed, gave a clear indication that, attention is never given to the Albinism community even if there is an outcry about their brutal killings. If the church can use the prophetic voice about their existence and care for those who are victims, that will bring security to them.
- c). Resolution 26/10 of October 2014 by Human Rights Counsel recommended without a vote that; the General Assembly should proclaim 13 June as the international Day of Albinism. This is the day that all stake holders including the church should make use of this platform to enforce the teaching about the handling the issue of Albinism
- d). That Albinism awareness be done in churches, but in a manner that will encourage them to be part of the church community and the community at large.



e). The church should join in solidarity with the government to stop the mistreatment that leads to the killing of people with Albinism.

f). A partnership with the local church to organize people living with Albinism in order to include them in the community, there is a need to rectify the misguided cultural myths in order to improve the quality of their lives.

g) With regard what culture has taught, it is the researcher wish to make note that People Living with Albinism has needs that includes being recognized as people who are being send by God to make a difference in this world, therefore they also need to be treated in a holistic manner. Therefore, further investigation on the truth about this silent belief that they disappear; and if it is true that they disappear; those family members who experience that, what have they done to solve the mystery of their disappearance? Why the culture is culture more vocal about their bad treatment and why has their discrimination been encouraged even though it is clear that this is just a myth?

## **8. Conclusions**

It has been indicated in the previous researches that people living with Albinism have suffered in many ways because of what the people have assumed. It will be best if they can be incorporated in the society, they live in. It has been indicated in this research that people living with Albinism have had many difficult times in the livelihood in every interview conducted. There is an element of discrimination that has been practice by almost every community that they live in.

The response of the family shows the need for intervention. The response to the pastor's interviews indicated a lack of pastoral care giving in the field of Albinism. The applied Pollard and Gerkin were tested and in all areas, it proved the point that there is a lot to be done in the field of Albinism and pastoral care.

In all this God has sent Jesus to this world to represent all human dignity, this means everyone is carrying God's identity through Him. He was sent as a shepherd to take care of the sheep; it is therefore proper to practice what Jesus has taught the world that; everyone carries a special identity that needs to be embrace by those who lives amongst. Everyone needs to be taken care of, whether by families and communities, that is a shepherd is send to look and for those sheep

that is lost, just as Jesus did. He came to save every human being, whether, disabled or not. We all have this responsibility of doing what He taught us to do, “Love one another, care for one another in order to create a comfortable space for all.

After all Luke 5: 31, Jesus answered, “It is not the healthy who need the doctor, but the sick” He took His time to walk and look for those who were destitute and cared and love them and then send them to their own community for them to belong.

**LETTER OF INTRODUCTION AND INFORMED CONSENT  
FOR PARTICIPATION IN ACADEMIC RESEARCH**

**Title of the Study:**

*CARING FOR AN A CHILD WITH ALBINISM: A PASTORAL CHALLENGE*

**Researcher:**

MARIA SHADIBO DIALE student number: 12380645

E-mail: revmsdiale95@gmail.com. Cell: 0722841711

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You are cordially invited to participate in an academic research study due to your experience and knowledge in the research area, namely **Albinism**. Each participant must receive, read, understand and sign this document *before* the start of the study. If a child is 7-17 years and is requested to partake in a research study, the parent/legal guardian must give consent. Children from 7-17 years are also required to sign an assent form.

- **Purpose of the study:** The purpose of the study is to understand the knowledge, perceptions and attitudes of township dwellers on issues around Albinism. The results of the study may be published in an academic journal. You will be provided with a summary of our findings on request. No participant's names will be used in the final publication.
- **Duration of the study:** The study is already at an advanced stage and its projected date of completion is August 2020
- **Research procedures:** The study is based on Albinism. Semi-structured and focus group interviews will be conducted.
- **What is expected of you:** The participants will be expected to share their knowledge, perceptions and attitudes on matters around Albinism
- **Your rights:** Your participation in this study is very important. You may, however, choose not to participate and you may also stop participating at any time without stating any reasons and without any negative consequences. You, as participant, may contact the researcher at any time in order to clarify any issues pertaining to this research. The respondent as well as the researcher must each keep a copy of this signed document.
- **Confidentiality:** All information collected through the interview will be treated within the strictest confidentiality. The tapes and the interview schedules will be kept for two years following any publications or for six years if no publications emanate from the study. The relevant data will be destroyed, should you choose to withdraw.

**WRITTEN INFORMED CONSENT**

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I hereby confirm that I have been informed about the nature of this research.

I understand that I may, at any stage, without prejudice, withdraw my consent and participation in the research. I have had sufficient opportunity to ask questions.

Respondent: \_\_\_\_\_

Researcher: \_\_\_\_\_

Date: \_\_\_\_\_

Contact number of the Researcher: \_\_\_\_\_

**VERBAL INFORMED CONSENT** (*Only applicable if respondent cannot write*)

---

I, the researcher, have read and have explained fully to the respondent, named

\_\_\_\_\_ and his/her relatives, the letter of introduction.  
The respondent indicated that he/she understands that he/she will be free to withdraw at any time.

Respondent: Name and Surname \_\_\_\_\_

Researcher: Name and Surname \_\_\_\_\_

Witness: \_\_\_\_\_

Date: \_\_\_\_\_

**ANNEXURE B**

**RESEARCH QUESTIONNAIRE FOR THE MASTER OF ARTS (PRACTICAL THEOLOGY) RESEARCH PROJECT**

**RESEARCH TITLE: CARING FOR A CHILD WITH ALBINISM: A PASTORAL CHALLENGE**

***PERSONAL DATA OF INTERVIEWEE:***

**Gender.....Male.....Female.....**

**Nationality.....**

**Age: .....**

**Marital Status:**

**1. How many of your Children have Albinism.....?**

**2 Can you share about your journey with Albinism?**

.....  
.....  
.....  
.....

**3. a. Share with me, what comes to your mind when holding or looking at your baby?**

.....  
.....  
.....

**b. What information can you share bout the issue of Albinism?**

.....  
.....  
.....

**c. What troubles you about their lives?**

.....  
.....

**4. A. How do you feel when people share negative thoughts about them?.....**

.....  
.....  
.....  
.....

**b. At what point do you need to be relieved from caring for them?**

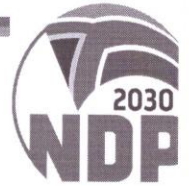




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**MADIBENG SUB-DISTRICT**

TO ETHICS COMMITTEE

**Re: CONFIRMATION OF SOCIAL WORKER'S ASSISTANCE IN CONDUCTING PARTICIPANT RESEARCH INTERVIEWS FOR RESEARCH TOPIC: CARING FOR A CHILD WITH ALBINISM: A PATORAL CHALLENGE BY REV. SHADIBO DIALE (12380645)**

Confirmation to assist Rev Shadibo Diale with student number 12380645 with interviewing, moderating and debriefing participants for her research. The details of the interview is as follows

- The interviews will be held in Rustenburg as well as the surrounding areas
- They will be held in a safe and conducive environment which is private and comfortable for the participant. This is to enable participants to disclose freely, were confidentiality is assured as the topic of choice is very sensitive.
- The venue of the interviews will be either in the comfort off the participants homes, the researcher's home or any place where the participants deemed comfortable and where there is privacy
- The interviews will take an average time of 1 hour to 2 hours
- The interviews will include debriefing sessions where necessary/ Should need arise
- I have reviewed the interview questions and they are appropriate for its intended purpose, should I be unavailable for an interview due to work commitments and unforeseen circumstances Rev. Shadi Diale may continue with the interviews in my absence.

Your assistance in this regard will be highly appreciated

**Social worker**

Emmie Mooki

  
**Signature**

SACSSP NO: 10-29980

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