



**SCHOOL OF RELIGION, PHILOSOPHY AND CLASSICS**

**An ethical analysis of the African traditional  
beliefs surrounding people living with albinism in  
South Africa.**

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## **Dedication**

To my late grandmother, Thandi Ester Ngubane

To my late grandfather Lawrence Godfrey Ngubane

To my late Father, Simo Petros Magubane

## **Acknowledgement**

To my Lord be the glory. I am indebted to give thanks to my Lord and savior Jesus Christ who gave me the strength and health through my journey. I never could have made it without you. Thank you, father.

To my Mother, June Nomasonto Ngubane, ngithi Mbovu, Ngcukumane, Somahhashi Nyoni Yamaphikela Esidwa Isisila sayo. Dear Mother. This Master's degree is yours. I would never thank you enough for all the hard work and sacrifices you have done for me. All I ever dreamed of was to make you proud. Thank you for allowing me to take time off my parenting duties, words will never be enough to thank you. Thank you Totoh.

To my Daughter, Unathi Mpilwenhle Ngubane, one of the biggest motivations was that you will be able to read this one day. I might have taken too much time off my parenting duties, but I knew you were in safe hands. You are my focus. Thank you, Nana.

To my siblings, Njabulo, Nontokozo, Ntokozo, my nephew Nkosinathi, my niece Eminathi and my uncle Siphso. Thank you for being my cheerleaders, at times I wanted to give up but thank for the everlasting love and support. Ngcukumane.

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## **Abstract**

This dissertation offers a critical ethical analysis of African traditional beliefs surrounding people living with albinism. It argues that people living with albinism are socially excluded in some African traditional communities because they are not perceived as human beings. This dissertation provides an overview of some of the African traditional beliefs surrounding albinism, through a desk top study. Albinism seems to be a two-edge sword: on the one hand, it is believed that people with albinism are born with special powers that can bring wealth, and that their body parts can enrich people. On the other hand, people living with albinism are believed to bring bad luck and that having relations with them will bring bad luck. The Study highlights beliefs and perceptions such as: PWA are perceived as Ghosts, having sexual intercourse with a person living with albinism can cure HIV and AIDS and the body parts of people living with albinism can make a good portion of muti. As a result of the above beliefs, people living with albinism often live in fear of being killed, raped, discriminated against, alienated and abducted. It is against this backdrop that this dissertation, through the lens of Limited communitarianism, which is closely related to the right-based approach argues that albinism is a disorder which results in pigmentation therefore there is a need to ensure proper education to the community regarding albinism. Furthermore, the dissertation argues that people living with albinism are humans with rights and they are not ghost, therefore they should be respected for their humanity.

**Keywords:** African traditional beliefs, Albinism, African communitarian Ethics, The right-based approach, lack of knowledge

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## **Acronym**

NGO	Non-Governmental Organization
PWA	People With Albinism
UTSS	Under The Same Sun
SA	South Africa
HIV	Human Immunodeficiency Virus
AIDS	Acquired Immunodeficiency Syndrome
ASSA	Albinism Society in South Africa
CEO	Chief Executive Officer
KZN	KwaZulu-Natal
NOAH	National Organization for Albinism and Hypopigmentation

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## **Chapter one - Introduction**

### **1.0 Introduction**

This dissertation is a critical analysis of African communitarian understanding of a person for the enhancement of the well-being of people with albinism (PWAs). The current chapter encompasses of the background of the study, the research aims and objectives, as well as the problem statement. The aim of this chapter is to provide a brief outline of the study and provide summaries of the key components of the dissertation.

There have been several conceptions surrounding people living with albinism. This has resulted in negative consequences on the people living with albinism. Scholars like Mswela (2011) have described how people living with albinism live in fear of being hunted and killed for their body parts. In a similar vein, Elvis Imafidon (2017), has explained that the misconception about albinism is due to the lack of understanding about albinism as a disorder. In South Africa for instance, the violent attacks and brutal killings of PWAs have alerted the community of the difficulties faced by PWAs and their families.

The number of people living with albinism is very minimal (Salewi : 2011), they are a very small minority of citizens in South Africa. As a result, the community sees them as species, instead of appreciating them for their humanity. Most of the South African community has had many assumptions about the disorder as a means of trying to justify the physical difference between people living with albinism and people without albinism. This has resulted in many unanswered questions that the community seeks to know. One can assert that the attacks, violent killings, and stigmatization of people living with albinism in South African communities are the consequences of lack of knowledge among citizens about the disorder. Because of this lack of knowledge, people have different perceptions about this disorder, resulting in the assumptions, myths, and superstitions associated with this disorder (Cruz-Ingo 2011). From my personal observations, the assumptions themselves have two contradicting views; first, there is the assumption that people with albinism bestow luck and therefore, their body parts can bring wealth, success, and luck; second, there is an assumption that regards people living with albinism as people bestowed with bad luck (Salewi : 2011).

One notes that, people living with albinism are faced with social challenges that they must fight daily. One of which includes the challenge of having to live in fear of being hunted for their body parts (Cruz-Ingo 2011: 79). Their body parts are hunted for different reasons: it is believed that their body parts are good or potent for traditional rituals such as making *umuthi* (*umuthi* is traditional medicine used by South African people, usually to heal people). The rights of people living with albinism are infringed and violated upon in different ways.

These perceptions have greatly affected the living experience of PWA. This dissertation is an inquiry into how limited communitarian theory and the right-based approach can inform the African traditional beliefs on albinism and how the community perceives people living with albinism.

### **1.1 Background**

Albinism is the pigmentation of the skin, the eyes and hair, which is “a genetically inherited” disorder (Hongs 2006: 06; Bila et al. 2005: 01). It is thought to be more common in Sub-Saharan Africa and affects about 1 in 4000 people in Africa Salewi (2011: 01); Ross (2015: 01). Due to the misconception of the disorder, PWA are faced with social exclusion as a result of the community’s lack of understanding of the disorder. Imafidon (2018), who lives with Albinism himself, has written a book on albinism from a philosophical perspective. Under the section on “the epistemology of albinism,” he explains that the lack of knowledge about this disorder has resulted in the community finding justification for the pigmentations. As a result, this has led to the misconception, myths and beliefs surrounding this disorder. There are different beliefs surrounding this disorder with some contradicting themselves. For example, some people believe that PWA bring bad luck while others believe that they can be used as a means of acquiring wealth. As a result, PWA are an outcast in the community. Within most of the African communities, it is difficult for people to accept what is different from the usual, hence, PWA are referred to as “it” or seen as the “other”. Imafidon (2017 and 2018), asserts that for African people, it is hard to accept the usual, thus, anything unusual is problematized. According to Imafidon, there are seven types of albinism, OCA2 being the most common in Africa, the other types of albinism will be discussed further in chapter two.

It must be noted that there is no cure for albinism, but one can live a happy and healthy life, if they take care of themselves. PWA do not only face social challenges but they also face health related issues, some of which include facing difficulties in their academic career, which is due to the pigmentation of the eye leading to visual difficulties. Resultantly this condition makes reading from the screen and textbook a big challenge for them. Dapi et al. (2018: 11) affirm that eye pigmentation has resulted in some PWA being unable to complete their academic programmes due to their inability to see clearly. In South Africa, most PWA live in fear as a result of the African traditional beliefs that the community has about this group. In recent years, the killings of people living with albinism have escalated to the extent that the well-respected Zulu King Zwelithini spoke about this matter to the community. In his statement, the king mentioned that PWA are human beings and went on to condemn their killings. His opinion on the matter is very important because he is an influential person in the Zulu traditional community (Khomu, 2016: 2). For the full article on the Kings perception of the killings and attacks of people living with albinism in South Africa see Appendix 2.

## **1.2 Motivation of the study**

In South Africa, the month of September is annually marked as albinism month. During this month, there are various awareness programmes. The awareness programmes run for a week to educate people about albinism, and most importantly, how those affected by it can manage the disorder. Despite the awareness programmes, there seems to be an increase in the amount of reported cases of killings relating to people with albinism. There is a Non-Governmental Organisation (NGO) that deals with cases on albinism in Africa, this NGO releases statistics of reported cases on attacks and killings of people living with albinism. The 2019 report showed that the number of cases had increased when compared to the 2015 report (Under the Same Sun report, May: 2019). In February 2018, a 13-year-old Gabisile Shabane was abducted from her home, she was living with albinism, and was found almost after a month of having been reported missing. Her body was found in a shallow grave with some of her body parts missing. It was later discovered that the 28-year-old man who was arrested for her murder was sent by a *Sangoma*, (a sangoma is a traditional healer) to get body parts of any albino to make the 28-year-old man's business

flourish (ANA, 2018: 1). The South African albinism society chairperson, Mrs. Nomasonto Mazibuko, who was interviewed on SABC news in February 2016 in relation to the increasing number of people living with albinism, affirmed that “language is still a problem, many people who have this disorder or condition are called “it”. As a result, people living with albinism are not valued or respected for their humanity.

These incidences motivated the study in assessing the myths and perceptions of people with regard to people living with albinism

### **1.3 Research problem**

The problem that the study seeks to explore and interrogate is that there is misunderstanding around albinism because they are different and as a result they are not safe in their communities. This is done by analyzing how the theory of African communitarianism and the right-based approach can be used in the development of a trustworthy understanding of albinism in South Africa and beyond. This process will be guided by the following questions: (1) what are the beliefs associated with albinism in South Africa? (2) What are the effects of the beliefs that the community have towards PWA? (3) How can the African limited communitarianism theory challenge the people’s beliefs about albinism? (4) Can the limited communitarianism close the knowledge gap in the contemporary discourse on albinism?

The stigmatization of PWA is one of the major issues faced by Africans living with this disorder. Mswela (2011) argues that the stigmas, myths and superstitions, brutal killings, and social exclusion of PWA are issues in contemporary South Africa. In addition, Imafidon (2018) avows that the above issues are as a result of beliefs associated with albinism. It must be noted that albinism does not affect a large number of the population hence, majority of the people do not understand this disorder and try to find their own answers as to what albinism truly is, which has resulted in a number of beliefs about albinism.

### **1.4 Key Question**

How can limited communitarianism and the rights-based approach inform perceptions, beliefs, and treatment of people living with albinism?

### **1.5 Research sub Questions**

1. What are the beliefs of people regarding albinism in most traditional communities in South Africa?
2. How do these beliefs and misconceptions affect how people living with albinism are treated?
3. How can Limited communitarianism and the rights-based approach reorient people's beliefs and treatment of people living with albinism?

### **1.6 Key Objective of the study**

To assess how limited communitarianism and the right-based approach can influence perceptions, beliefs, and treatment of people living with albinism

### **1.7 Objectives**

1. To ascertain people's beliefs with regards to albinism in South Africa
2. To discuss the effects of people's beliefs towards albinism
3. To explore the values of limited communitarianism that can inform people's beliefs about albinism

### **1.8 Language use**

The term Albino is offensive to people living with the disorder. This is because if one says Albino, they are referring to the disorder as opposed to the person living with the disorder. According to Baker (2011: 02) "the label albino is considered inappropriate and the term persons with albinism is acceptable because it puts the individual before the condition." The researcher found this discriminatory that people should be called by their disorder because they are not the disorder, but they are living with the disorder. As a result, for this dissertation, the study will use people living with albinism and PWA as an abbreviation.

### **1.9 Key Focus**

The African traditional beliefs surrounding albinism have led to violent attacks, killings and the discrimination of people living with albinism. Elvis Imafidon (2017: 160) asserts that:



African moral humanism justifies the cruel treatment of persons with albinism. When persons within an African community causes harm, maltreat, stigmatize and discriminate against persons with albinism, they do not often feel they are doing something wrong in the same way they are feel that they are hurting a fellow human... their interaction with a person with albinism, cruel as it may be, is not considered the same as an interaction they would have with a fellow human being the ill-treatment of persons with albinism protects the community from harm.

This dissertation focusses on the African traditional beliefs surrounding albinism, which have led to cruelty towards people living with albinism. This study analyzes the beliefs through African communitarian Ethics.

### **1.10 Research Methodology**

This research is a desk top research based on secondary sources. Using this approach, the study relies on both unpublished materials and published materials mostly originating from journals articles, theses, dissertations, and books. In investigating and analysing the aforementioned research topic (The African traditional beliefs surrounding albinism) the study uses a systematic literature review. This is of benefit to both the researcher and the reader because if work is divided into relevant sections, it makes it easier for the reader to allocate the key issues regarding the phenomena. In addition, the literature review is arranged according to themes. This is because scholars have written from different perspectives and the ones that are closely related are placed under one section. For example, scholars that have explained and described albinism are in one section, whereas scholars who have written about the beliefs surrounding albinisms, for instance, have been arranged according to their ideas, in the section of beliefs. The literature review is important, it helps the researcher to identify key issues about a phenomenon. Moreover, there has not been an extensive research done on the matter and this therefore allowed the study to locate the gap in literature and to know where further development and research is needed in a particular area. Leedy (1997: 195) asserts that a research design as a strategy for a study which will provide the overall outline for data collection. As mentioned above, the study relies on secondary sources that were obtained from different platforms, which include: Sabinet,

Research gate, and Google scholar. The research methodology, according to Schwab (2007: 195), is a system of how an investigation should proceed. This study makes use of two methodological approaches namely, the exploratory and descriptive approaches. Exploratory research is a research used to investigate a problem and have a better understanding of an existing problem. Burns and Grooves (2001: 374) define exploratory research a type of research commonly conducted to attain new understandings, develop new perspective on a phenomenon, and increase existing knowledge regarding a certain phenomenon. The study uses this approach to gain new knowledge about albinism, discover new ideas about albinism, and increase knowledge from what has been said by other scholars regarding albinism. The main objective of such research is to clear uncertainties about a phenomenon. This study aims to clear the uncertainties about albinism by showing the beliefs to be invalid and inconsistent. The second methodology adopted in this study is the descriptive methodological approach. Defined by Streubert and Carpenter (1999: 49), descriptive research “involves exploration, analysis and description of a particular phenomenon, as free as possible from unexplained, presupposition aiming at maximum intuitive representation”. In addition, Marshall and Rossman (1995: 49) assert that a descriptive study is conducted as means to “document the phenomenon of interest in the real situation”. The study describes the effects of key issues that were discovered in chapter four.

### **1.11 Theoretical Framework**

#### **Communitarian understanding of personhood.**

According to the Oxford Dictionary of Philosophy, “Communitarianism is a model of political organization that stresses ties of affection, kinship, and a sense of common purpose and tradition” (Blackburn 1995). Masolo (2010: 231) asserts that “Nego-African societies put more emphasis on the group than on the individual, more on the solidarity than on the activity and needs of the individual, more on the communion of persons than on their autonomy”. As a result, the well-being and the success of the group is more important than the individual in the African community. Unlike the modern community, which is individualistic and capitalistic, the African traditional community was the type that valued unity and the betterment for all. Hence, one can say that the disadvantage of

such a community is that the needs of individuals are overlooked. There are three forms of communitarianism, they include the following:

### **Radical communitarianism**

John Mbiti (1970), Placide Tempels (1959), and Ifeanyi Menkiti (1984) are the three classical proponents of radical communitarianism. Bernard Matolino (2014: 71) asserts that the above three named scholars “believe that African reality is construed by the reality of the community”. According to Radical communitarianism, importance is given to the responsibilities, which individuals has towards the community, and the right of individuals are not prioritized. What is common about these three scholars is that they ascertain that in African tradition, the community takes precedence over the individual. Mbiti (1970), avows that an individual has no existence outside the community. In addition, Menkiti (1984: 171) states that “a man is defined in the envioning community”. The above-named scholars agree that there are processes one needs to go through as a procedure of being incorporated with or by the community. For example, when it comes to initiation among most Xhosa speaking people, in order for young men to be considered men in the community, they are required to go to the mountain, and only upon their return will the community declare them as men. This is an example of how the community can define who one is in that community.

### **Moderate communitarianism**

Moderate communitarianism is a view presented by Kwame Gyekye. It is an objection to radical communitarianism but on some level, these two theories have similarities, one of which include the primacy of the community. Etzioni (1998) affirms the main aim of Moderate communitarianism is to bring together the issue of rights and social responsibility, meaning that this theory was proposed to balance social forces and individual independence. In a similar vein, Gyekye (1997: 41) ascertains that “moderate communitarianism aims to ascribe to both the community and the individual an equal moral standing”. Unlike radical communitarianism, which only prioritizes the community, moderate communitarianism is of the notion that rights, and responsibilities have equal status. In a book titled *Personhood in African Philosophy*, Matolino (2014) asserts that the key defining characteristics of moderate communitarianism is that Gyekye “sees this

radicalism as erroneous, hence he seeks to show that there are certain things that only belong to the domain of individual struggles and cannot be shared with the rest of the community” (2014: 63). The main idea behind moderate communitarianism is that the community does not override the rights of an individual, hence, the two should be considered equal.

Using the two types of communitarianism mentioned above would have a conflict of interest with the aim of this study. This is because both theories promote the importance of the community over the individual. Radical communitarianism focuses on the rights of the community more than on individual rights. If one should use this theory, then the theory will allow the community to continue to do anything that they do towards people living with albinism. This is because this theory places the community above the individual. Moderate communitarianism, on the other hand, holds that the community’s rights and the rights of individuals are equal. By using this theory there will be a conflict of interest because both the interest of those living with albinism and the interest of the community will be equal, whereas this study aims to show that people living with albinism should be respected as individuals before the being referred to as a community member. It is therefore important that the study finds a theory that firstly, is recent communitarianism, which focuses on the contemporary community and secondly, considers the rights of people living with albinism and will advocate for the punishment of those who infringe on the rights of others.

### **1.11.1 Limited communitarianism**

As an objection of radical and moderate communitarianism, Bernard Matolino (2014) proposed the concept limited communitarianism, He objects the radical and moderate communitarianism because these two theories fail to take the individual seriously. He asserts that “limited communitarianism differs quite significantly from moderate communitarianism in some important respects” (Matolino 2014: 161). He avows that the main difference between these theories is the area of rights and the issue of primacy of the community over the individual (Matolino 2014: 161). Limited communitarianism is of the notion that there are some rights that should not be taken away from people or that can never be broken. Limited communitarianism advocates for a different meaning or

understanding of the community. Matolino argues that “individuals are entities and that they are worthy of respect as a creation of God and her identity proceeds from God” (Matolino 2014: 183). This means that no matter how physically different a person might be, they should be respected for their humanity. This theory is useful to this research because it addresses both parties involved. That is, it addresses people who violate the rights of others as well as those whose rights are violated. As a result, by using this theory, the study challenges how the community violates the basic rights of people living with albinism.

### **1.11.2 The Rights-based approach**

The second theory used in this dissertation is the rights-based approach. The rights-based approach to moral and political theory has its origins in the work of John Locke (1632-1704), Jean-Jacques Rousseau (1712-78) and Thomas Hobbes (1588-1679). All the philosophers mentioned above are amongst the originators of the social contract theory. The social contract theory understands the political authority to generate and apply regulations and, by extension, the force of moral norms, to be grounded in a descriptive narrative called the ‘social contract’. The rights-based approach is primarily based on social contract as agreed upon by a group of people. This social contract theory advocates that people’s moral obligations are dependent upon agreement among them to form the society in which they live. This means that rules and norms are set by a group of people who come to an agreement on what is acceptable and what is not acceptable in that particular living space. As a result, society will have to come to an agreement on what they think or perceive as right and acceptable. Consequently, the people of that society will be obligated to follow such rules. To elaborate on this further, this study made use of example of South Africa in connection to the study. In South Africa, it was agreed that the country is a democratic country and that people are bestowed with rights. This means that the society is obligated to respect each other’s rights, and everyone is obligated not to infringe on the rights of another.

According to Dworkin (1970: 7), the aims and objectives of rights is to protect individuals against certain decisions that a majority might want to make, even when that majority acts in what it takes to be general interest. Looking at the above objectives provided by the

foregoing scholars, and in reference to people living with albinism, it must be noted that one of the most common objective is to protect people living with albinism against some decisions that a majority might want to make concerning them, even when majority acts in what it takes as a the general interest. So, in brief, rights protect people living with albinism from being used as means to achieving certain goals. In addition, Clements and Reads (2008 :1), assert that “Human rights has increasingly come to be a significant framework both to aid the understanding of those who face oppression and to underpin social, legal and political measures to encounter it”. With the above, it must be said that the objectives of human rights are to ensure that no one is deprived of their rights, even if it means that a large group of people think that they should. When connecting the above to albinism, it is clear that the community’s perception of who they are does not allow them to violate their human rights.

### **1.12 Significance of the study**

The purpose of this study is to assess how limited communitarianism and the rights-based approach can inform the perceptions, beliefs, and treatment of people living with albinism. In this study, beliefs are those which concern the community, people living with albinism, and the families of people living with albinism. With the number of cases against PWA being reported to the police, there has been an increase in the attacks and murders of PWA in African communities. It is important to note that in an African context, belief is an important form of knowledge passed on from generation to generation, which eventually becomes a societal norm. Elvis Imafidon (2017: 53) emphasizes that people gain knowledge consistently. For instance, people will familiarize themselves with a phenomenon if there are shared beliefs about it, and the beliefs will become a norm. The overall purpose of this study is to assess the beliefs surrounding albinism through an African communitarian ethic. African Communitarian ethics serve as a guide to how people conduct themselves to ensure solidarity, which is one of the most important value in African communities.

### **1.13 Structure of the study**

Chapter one is the introductory chapter. It introduces the study by giving a general overview of the research. It begins with the background, which explains the phenomena

that the study focuses on. It also provides a motivation for the study, which is a real-life story of a 13-year girl who lost her life. Chapter one also provides a guide for the research. It further highlights the objectives of the study and a summary of the theoretical framework. The research methodology is a detailed description of how the research was conducted. The study uses the exploratory and descriptive methodological approaches. The study explores the African traditional beliefs surrounding albinism and describe how the African traditional beliefs surrounding albinism negatively affect the lives and family of persons living with albinism.

Chapter two is the literature review. The aim of the Literature review is to review books, scholarly articles, and all the relevant material in connection to an issue, or research area, doing this will assist the researcher to summarize, describe and evaluate work from other scholars that will assist in investigating the research problem. The objective of a literature review is to outline and describe what other researchers have found and demonstrate how a research would fit within a larger field of study. The study uses a systematic literature review. This was done by arranging articles according to themes. The scholars who have defined albinism are under one section and those who have discussed issues affecting people living with albinism are arranged in another section. All that has been discussed in chapter two were referred to at some point of the study. Chapter two covers the literature that has been written by scholars from different disciplines including philosophy, human sciences, anthropology, social work, and social science, just to mention a few. It must be noted that the majority of the scholars used in the literature review advocate from the legal, philosophical and anthropology perspective. This is because people living with albinism are discriminated against at many levels. The chapter also includes the work of Alvis Imafidon, who is living with albinism. He has written from a philosophical perspective.

Chapter three is the theoretical framework. Chapter three outlines the theory that is adapted by this study. The introduction of communitarianism (Limited Communitarianism) and the rights-based approach as important theories give the study guidance when it comes to assessing African traditional beliefs concerning albinism. This is helpful in terms of revealing key issues that result from the beliefs. The right-based approach is closely related

to Limited Communitarianism and were be used as justification for what has been advocated for by limited communitarianism.

Chapter four is the analysis and findings. This chapter is important because its serves as a lens through which one studies or analyses a phenomenon. From the theory used in chapter three, the key issues or the main areas which the theory advocates for, is used to study the main research question. The study looks at the beliefs about albinism, highlights them using the key components of Limited communitarianism while the rights-based approach is used as a means to justify the claims of limited communitarianism. In chapter four, the study highlights the common beliefs surrounding albinism. People living with albinism are believed to be a curse, a cure for HIV and AIDS, and considered not as human. In chapter four the study argues that these beliefs are false and that cannot be proven. To answer one of the key questions of the research, which has been discussed in chapter one, the study discusses the effects of the African traditional beliefs on albinism. People living with albinism live in fear, are discriminated against, and socially excluded. These are some of the implications of the African traditional beliefs on albinism.

Chapter five includes the summary, recommendations, and the conclusions. This chapter provides a summary of the whole study. There is a brief discussion of what each chapter entails and the key issues that resulted from each chapter. This is followed by the recommendations that the study thinks are important for the relevant parties. The recommendations are made as a means of encouraging the social involvement of people living with albinism and how the community can familiarize themselves with people living with albinism. Lastly, the fifth chapter discusses the conclusion which brings the study to an end. The conclusion is as important as any other part of this study because here, the study explains whether it was able to answer its research questions, and to indicate whether the study successfully met its set out objective.



## **Conclusion**

This chapter has introduced the reader to the study. It has provided a detailed outline of the overall study. This has laid a foundation for the discussion of the purpose of the study. The chapter is important because it provides an in-depth outline of what the study intends to do.

Chapter two is the literature review. It surveys books and articles that have been written on the same phenomena. This section made use of systematic literature review. This means that topics were divided into subsections according to the similarities of the themes that each reviewed article addresses.

## Chapter Two – Literature Review

*“People living with albinism in Africa are a vulnerable group of people who are under the threat of extinction as they are killed with impunity based on the belief that the potion made from their body parts can bring luck, wealth and success” (Salewi 2011: 10).*

The quotation above by Salewi is of significance to the study. This is because it captures the reality of people living with albinism in Africa. It exposes the realities of people living with albinism in Africa. The above quotation is a strong statement that shows that attention is needed regarding issues affecting people living with albinism.

### **2.0 Introduction**

The previous chapter was the introductory chapter. It provided an overview of the entire study as well as the important features of the study, some of which include: the background of the study, the main question, the research problem statement, the objectives as well as the outline of the dissertation. The current chapter presents a review of relevant literature in accordance to the goal of the study. According to Arlene (2019), “Literature reviews are designed to provide an overview of sources that a researcher has explored while researching a particular topic and to demonstrate how a particular research fits within a larger field of study”. This chapter looks at the literature that has been written by scholars from different disciplines including philosophy, human sciences, anthropology, social work, and social science, just to mention a few.

The type of literature review that was adopted by this research is called systematic literature review. According to Rocco (2016), a systematic literature review “consists of an overview of existing evidence relevant to a clearly articulated research question, which uses pre-specified and standardized methods to identify and critically evaluate relevant research, and to collect, report, and analyze data from the studies that are included in the review”. The goal is to purposely document, assess, and summarize logically all research conducted about a clearly defined research problem. Typically, it focuses on the type of questions that

are very specific and practical, often posed in a cause-and-effect form, such as: how does beliefs surrounding albinism affect people living with albinism, how does the beliefs contribute to the misconceptions that the community has about albinism, or to what extent do the beliefs surrounding albinism contribute to misconceptions surrounding albinism. In connection to this topic, one may ask how the African traditional beliefs affect the lives of people living with albinism. This type of literature review examines research related to the topic.

The purpose of a chapter like this is to give the reader a deep insight on the phenomena, have a better understanding on it, and come to terms with what other scholars have had to say about it. The chapter is of benefit to the writer and the reader because it serves as a guide to what has been said or argued as well as what has been left out or overlooked by other scholars. This chapter assesses what has been written on albinism.

When seeking to find an in-depth understanding about albinism, one cannot overlook the work of Alvis Imafidon, who is living with albinism. Imafidon has written a book on albinism from a philosophical perspective titled *African philosophy and the otherness of Albinism*. The aim of this book is to explain why people living with albinism are excluded in the African community. Imafidon writes about the lack of knowledge, as well as the ontology of people living with albinism, and recommends that the government should find means to ensure that the community has better understanding of albinism. John Makumbe from Zimbabwe, who was living with albinism, is one of the people who broke down the prejudice of albinism and fought for the rights of people living with albinism in Zimbabwe. Maureen Mswela from South Africa, who also advocates for the rights of people living with albinism has written articles on the rights of people living with albinism in South African, for example *Colour discrimination against persons with albinism in South Africa* (2013). Diana Henry Salewi, who is also a Human right advocate of people living with albinism in South Africa. The above scholars are the main scholars who have written about albinism and advocated for the rights of people living with albinism from different perspectives.

## **2.1 Defining albinism**

Albinism is the absence of pigmented hair and skin. People have their different conceptions of what albinism is, leading to many misconceptions as they do not have an understanding of the disorder. The use of the word albino is perceived to be offensive to people born with albinism, hence, people living with albinism (PWA) is the correct term to be used when making reference to someone who has inherited the disorder.

Albinism is the pigmentation of the eye, skin and hair, which is genetically inherited and non- contagious (Ester Hongs, 2006: 06; see also Nontobeko Bila et al. 2015: 01; Stine Braanthen and Benedict Ingstad 2006: 600). In a similar vein, Caradee Wright (2015: 27) asserts that albinism is a genetically inherited disorder that results from a lack of melanin and can be harmful to a person. Authors such as Abeshi et al. (2017: 81) and Wright et al. (2015: 27), similarly state that the type of albinism that is most common in Sub-Saharan Africa is called Melanosomal transmembrane protein which is commonly known as OCA2. This type of albinism is present when individuals have lightly pigmented hair, skin, lashes, and brow. Mmuso Pooe-monyemore et al (2012: 01) as well as Diana Salewi (2011: 01) similarly avow that there is a high prevalence of albinism in Sub-Saharan Africa. Furthermore, Saweli (2011: 01) acknowledges that this inherited disorder is said to affect at least 1 in 400 people. As a result, it is rare for one to give birth to a person living with albinism. Thus, maybe indicative of why a minimal amount of people understands what it means to have a child with albinism and consequently leading to many misconceptions on albinism. This has led to people living with albinism being socially excluded and being vulnerable group of people in South Africa. In the North of South Africa, among the Sotho people, albinism is said to have a high prevalence compared to other ethnic groups (Patricia Lund and Retha Gaigher 2002: 365).

## **2.2 The types of Albinism**

Oculocutaneous albinism affects the eye, skin and hair. NOAH is an NGO that educates people about albinism and helps people affected with the disorder to manage the disorder. According to an article by NOAH there are seven types of albinism namely “OCA1, OCA2, OCA3, OCA4, OCA5, OCA6, and OCA7”. Martin Nelwan (2018: 01) states that “each of the types of albinism varies by the type of genetics that need to meet or be absent to produce

a certain kind of albinism”. The most common type of albinism in Sub-Saharan Africa is OCA2 (Wright et al. 2015: 28; Abeshi et al. 2017: 81). The following sections explains each of the seven types further:

### **2.2.1 Tyrosinases related Albinism**

This type of albinism is commonly called OCA1. It is a result of a genetic shortcoming in an enzyme called tyrosinase. OCA1 is divided into two subtypes OCA1a and OCA1b, which leads to white hair that may darken to blond, yellow or somewhat orange even light brown hair. This includes slightly more pigment in the skin (NOAH 2014: 2).

### **2.2.2 Melanosomal transmembrane protein**

The second type of albinism is commonly known to be OCA2 albinism, is P gene albinism. Protein genetic albinism is as a result of a genetic defect in the (P), that is, protein that helps the tyrosinase enzyme to function (NAOH 2014: 3). According to Under the Same Sun Report (2013), this type of albinism is the type that is most common in Tanzania. While authors such as Abeshi et al. (2017: 81) and Wright et al. (2015: 27) similarly state that this type of albinism is most common in Sub-Saharan Africa.

### **2.2.3 OCA3**

According to Abeshi et al. (2017: 81), OCA3 is considered a relatively mild subtype and in the rare non-African cases, reddish hair has been reported. OCA3 has an estimated prevalence of 18,500 in Africa. It is rarely seen in other populations (2017: 2). The street name for this type of albinism is ginger.

### **2.2.4 OCA4**

Abeshi et al (2017: 81) asserts that “individuals with OCA4 are usually recognized in the first year of life and generally have some hair pigment with the color ranging from silvery white to pale gold”. In addition, the color may get darker as the person gets older but the change is not very significant from childhood to adulthood.

### **2.2.5 OCA5- OCA7**

The above types of albinism were recognized in humans in 2012 and 2013. “They have reported mutations on three additional causative genes. As gene testing becomes available,

and more people with these types of albinism are identified, the complete range of physical manifestations will be recognized and may overlap with other known types of OCA. Currently, these types of albinism are considered to be uncommon” (NOAH 2014: 4), not much has been discovered about these types of albinism because they were recently discovered.

### **2.3 Genetics of albinism**

According to NOAH (2014: 4), “The genes for OCA are located on “autosomal” chromosomes. Autosomes are the 22 pairs of chromosomes that contain genes for our general body characteristics compared to the one pair of sex chromosomes”. In addition, “there are normally two copies of these chromosomes, one of which is inherited from the father and the other inherited from the mother. For a recessive trait (like most types of albinism) to occur, both of the person’s chromosomes must carry that trait”. That means that most types of albinism result from inheriting an albinism trait from both the mother and the father who often have normal pigmentation. According to NOAH (2014: 4) “in this case, the mother and father are considered to be carriers of the albinism trait because they each carry a recessive gene for the condition but do not manifest the condition themselves. When both parents carry the albinism gene (and neither parent has albinism) there is a one in four chance at each pregnancy that the baby will be born with albinism”. This type of inheritance is called “autosomal\ recessive” inheritance (NOAH 2014: 4).

As a means of investigating the parental genetics that would produce a child with albinism, Abeshi et al. (2017) describe the genetics that result in one to be born with albinism. The study has suggested that there are two most common types of albinism, it describes the two as “Ocular albinism always most present with eye changes, while oculocutaneous albinism is always present with the hypopigmentation of their hair and skin” (Abeshi et al 2017: 80). Abeshi et al. (2017) have studied the scientific literature and disease guidelines to summarize the clinical utility of genetic testing for ocular albinism and oculocutaneous albinism. This study also includes the Clinical diagnosis involved in ophthalmological examination, testing of visually evoked potentials, and electrophysiological testing. The genetic test is useful for confirming diagnosis, differential diagnosis, for couple risk assessment, and access to clinical trials (Abeshi et al. 2017: 80).

## **2.4 The legal matters that affect people living with albinism**

The general assembly of the United Nations proclaimed the universal declaration of human rights on the 10th of December 1948. The declaration was set as a common standard of achievement for all persons and nations. Human rights are bestowed to someone from birth, regardless of their color, ethnicity, sex, religion, culture or educational background. The aim of the Human rights policy is to ensure equality in the society and to protect individuals, especially vulnerable people. According to the General assembly document of the United Nation (1948), “all human beings are born free and equal in dignity and rights”. They are endowed with reason and conscience and should act towards one another in a spirit of togetherness. This document also asserts that, “No distinction shall be made on the basis of the political, jurisdictional or international status of a country or territory, to which a person belongs, whether it be independent, trust, non-self-governing, or under any limitations of sovereignty” (General assembly document of the United Nation: 1984).

In 1994, South Africa was declared a democratic country. Thereafter, South African legislature passed its constitution in 1996. Chapter two of the constitution is the bill of rights. According to the constitution, “Human rights are those basic and fundamental rights to which every person, for the simple reason of being human, is entitled”. These rights are incontrovertible thus, a person has them forever and they cannot be taken away (Currie and De Waal: 2005). The natural rights of South Africans received no protection before the country became a constitutional democracy in 1994. Now, fundamental human rights are entrenched in Chapter 2 sections 7 to 39 of the 1996 Constitution (Currie and De Waal: 2005). The Bill of Rights is arguably the part of the Constitution that has had the greatest impact on life in South Africa. As the first words of this chapter say: “This Bill of Rights is a cornerstone of democracy in South Africa. It enshrines the rights of all people in our country and affirms the democratic values of human dignity, equality and freedom” (The Constitution of South Africa, 1996).

When referring to laws and Acts found in the republic of South Africa, it is important to know how it came about and who passed such laws. The legislation of South Africa is the Acts and laws that require people to behave in a certain manner, whereas the legislature

are the members of parliament who sit in and discuss laws to be passed. Iain Currie and Johan Dewall in the Bill of rights handbook (2013: 42) point out that:

The term legislature refers to the institutions that exercise the legislative authority of the Republic: Parliament, the provincial legislatures and the municipal councils (Section 43 of the Constitution). The primary duty and principal form of conduct of all these bodies is legislating. The output of the legislative process-legislation of the central, provincial and local government, as well as any form of delegated legislation-must comply with the Bill of rights. This is because, in the words of section 8 (1), the Bill of Rights ‘applies to all law’. As far as conduct of the legislature and their committees and functions, such as the determination of internal arrangements, proceeding, rules and procedure.

This section of the literature review surveys the work of scholars have written from the discipline of law or the legal perspective. Most of the reviewed scholars are advocates of human rights of the PWA. When reviewing the legal perspective of issues faced by PWA one should not overlook the work of John Makumbe from Zimbabwe who broke down the prejudice of albinism and fought for the rights of people living with albinism in Zimbabwe. He also found the Zimbabwe Association of Albino’s in 1996, which was dedicated to looking after the welfare of people living with albinism (Lloyd Sachikhonye 2013: 2). Maureen Mswela from South Africa also advocates for the rights of people living with albinism in South Africa. Diana Henry Salewi, who is also a Human right advocate of people living with albinism in South Africa.

People living with albinism are vulnerable citizens of the country, yet, the protection and attention of people with this disorder is very minimal in South Africa. In recent times, there has been an increase in the killings and violent attacks against PWA (Under the Same Sun: 2019). These killings and attacks are due to myths and superstitions against albinism as a disorder. Salewi asserts that “The phenomenon is also attracting international attention as there is a public and international outcry against it” (Salewi 2011: 2). In addition, he claims that “this means that effort needs to be intensified both locally and internationally to check the scourge” (Salewi 2011: 2). The above statement shows that people living with albinism



do not have the opportunity to live a life like any other person and as a result, there is a need for intervention from the local government and international bodies.

Jean Burke (2014), Anita Franklin (2018), Maureen Mswela (2013;2017), Melodie Nothling-Slabbert (2013) similarly advocate that the rights of PWA are infringed and violated upon in Africa. Furthermore, the above scholars unanimously claim that the rights of people living with albinism are dishonored because of the myths, superstitions and beliefs associated with this disorder which results in the stigmatization of people living with albinism. In addition to this, the above scholars unanimously argue that PWA are discriminated against. Therefore, the current study intends to explore the African traditional beliefs and assess how the theory of limited communitarianism and the rights-based approach can be used to challenge people's beliefs and misconceptions as well as their attitudes towards people living with albinism.

Mswela (2017: 116), states that people living with albinism are killed for different reasons and sometimes these reasons contradict each other because one could be killed based on the belief that their body parts can bring wealth, while another could be killed because it is believed that they are a curse to the society. In addition, Burker et al. (2017: 114) argues against the unjust challenges faced by PWA and emphasizes that there should be social inclusion and freedom for PWA. Salewi, Makhumbe, Imafindon, and Mswela, who have written from the legal perspective, have written articles as a form of advocacy seeking for the protection of people with albinism.

NGOs such as Under the Same Sun has intervened to protect PWA. Under the Same Sun is an NGO in Africa that provides assistance to PWA. This NGO provides shelter for those who need to be placed in a safer environment, create awareness programs, and provide treatment surveys on PWA. According to a report made by this NGO, Tanzania have the highest reported cases of attacks and killing of PWA. Between the years 2013 and 2019, the report shows that there is still an increase in the amount of reported cases against PWA. *Appendix* three has three reports, dated 2013, 2015 and 2019. The reports show that, just like Tanzania, there is also an increase in the amount of reported cases in South Africa but most importantly there is an increase in the amount of people who were killed.

Some authors, including Franklin et al. (2018: 1) argue that “there is a growing recognition and acceptance in Africa that people with albinism should be considered as people living with disability” (Franklin et al 2018: 1). The authors use the “social-relational model of disability, which proposes that it is essential to understand both the socio-structural barriers and restrictions that exclude disabled people (they refer to this as barriers to doing) and the social processes and practices which can negatively affect their psycho-emotional wellbeing (they refer to this as barriers to being)” (Franklin et al. 2018: 2). They combined a “social model of disability with discussions on human rights to address the gap surrounding the psychosocial and daily experiences of people with albinism” (Franklin et al. 2018: 3). The authors conclude by claiming that the rights of people with albinism in some regions of Africa are not being endorsed. Their claims highlight the need to develop “a holistic concept of rights for children and young people with albinism which considers human rights as inseparable from those who are adults and without any form of disability”, (Franklin et al. 2018: 3). They have also highlighted some of the specific ways in which the lives of children with “albinism could be improved upon through addressing ‘barriers to being’ and ‘barriers to doing’, at the heart of which requires a shift in attitude and action to address discrimination” (Franklin et al, 2018: 4). The authors also look at the difficulties that children with albinism have, which include visual difficulties and they suggest that there are possible ways to overcome these challenges.

In a report published by the office of the United Nations high commissioner for human right (2013), there is a discussion on the rights of people living with albinism that are violated. The authors look at the rights people, in general, have and critique what is been done to people with albinism. They looked at the rights to a safe environment, the right to life, and the right to be an active participant in the society (United Nations high commissioners for human rights 2013: 5). The report examines how the attacks and the killings are against human rights. The author did not pay attention to independence of people living with albinism instead, the report just looked at the rights of people living with albinism from the legal perspective. It also overlooked how people living with albinism should be included in societal activities like finding careers, which is an important phase for every human begin.

Salewi (2011: 37) looked at possible ways that the government can effectively protect or try to end the killings of people living with albinism in Tanzania. In a similar vein, Mswela (2017) argues that the state has the duty to protect all its citizens, including PWA. In addition to this, Barker et al. (2014: 118) argues against the unreasonable beliefs that are associated with people living with albinism. The above authors are similarly advocating for the rights of people living with albinism.

## **2.5 Health related issues that affect people living with albinism**

People living with albinism suffer from many health-related issues. The most common among them is that they cannot be exposed to the sun without using sun protection creams. In addition, people living with albinism have difficulties seeing, the screens and textbooks, especially learners who are still at school. They also have a greater chance of getting cancer, compared to a person without the disorder. The authors that were be referred to below look at the health issues that are commonly faced by persons with albinism.

In a research conducted in 2002 on students living with albinism to check health related challenges that they face, Lund (2002: 367) avows that “86.8% of students complained of poor eyesight and 79% are sensitive to sunlight. This establishes that PWA do not only face social challenges but also health related problems resulting from the pigmentation”. Wrights (2017: 27) concurs that albinism is harmful to the person living with albinism because there are precautions as how they ought to live, this includes of making sure that they are well taken care of in the sun.

Similarly, Hongs (2006: 04) asserts that the majority of people living with albinism suffer from visual difficulties. One can also suggest that having the disorder can be a barrier to learning, which can have a negative effect on the learning experiences of students with albinism. For example, students with albinism have difficulties with eye site therefore they have challenges with seeing the board as well as using computers for a long time. The study conducted by Hongs also sees the need for learners to be placed in schools that are sensitive to issues regarding students with albinism. Hongs notes the need for support programs. Hongs proposes that programs that can be implemented should not only focus on health issues but also look out for psychological issues faced by PWA (2006: 25).

In addition to the above, Ray et al. (2016) also believe that people living with albinism have a greater risk of getting cancer. Hence, albinism is known to be a cancer prone disorder. Ray et al. asserts that, it is important for the people or a family with a child born with albinism to get educated as to how PWA manage the disorder. The most important management technique is that they need to make sure that they are not exposed to the sun. Ray et al. (2016) discuss ways in which one can manage albinism. According to them, it is important that PWA wear hats on hot summer days, it is also important that they wear hats as a means of protecting themselves from the sun because they are more likely to get cancer than others.

## **2.6 People with albinism live with fear**

A social issue is a problem that affects a considerable number of the individuals within the social order (Rubington and Weinberg 2010: 4). It is frequently a result of issues ranging beyond an individual's control and is the foundation of a contradictory belief on the grounds of what is supposed to be a morally just personal life or societal order. Some of these issues are social factors that psychologically affect persons with albinism.

The Under the Same Sun Report (2013) suggests that the increasing amounts of reported cases against albinism has resulted in some of the people living with albinism leaving their homesteads and to be placed in a safe environment because they are afraid of being hurt and being attacked. Due to myths about albinism, most of them leave their homes and are given a place in a shelter because their families fear for their safety. This report provides an overview of the amount of cases, which mostly include children, that have to be moved to temporary shelters as a means of getting them to a safe environment. The Under the Sun Report further asserts that "in the attempt to protect the fleeing children and adult with albinism, the government designed certain schools as temporary shelters" (The Under the Sun Report 2013: 3). There was a section in this literature review that fully discusses this NGO.

Bake et.al. advocate that "the myths associated with albinism in South Africa and Zimbabwe have a profound influence on the lives of people with the condition from the moment of their birth until their death" (2010: 169). They believe that "the beliefs and

superstitions surrounding the condition affect family life and interfere with access to education, employment and marriage”. They believe that these myths and superstitions associated with albinism have a negative impact on the lives of people living with albinism as well as the family members of people living with albinism. Consequentially, they compared attitudes to albinism in different cultures and groups and suggested ways in which the myths that have been associated with people with albinism for so long and frequently have very negative implications can be challenged by a more scientific and culturally neutral explanation (Bake at al. 2010: 169).

### **2.7 The Awareness Campaigns to enlighten the community about albinism**

Awareness raising is the act done as a means to educate and informing the people of your cause and campaign while hoping to activate an action from them in return or to simply have them better informed (Coffman, 2002). An awareness campaign usually involves detailed preparation and implementation. The following looks specifically at albinism campaigns.

Some author’s such as Masanja et al. (2014) emphasize that there is a lack of understanding of what albinisms is. This lack of understanding creates a bad attitude towards albinos, which in turn leads to the creation of these myths and superstitions. This is as a result of the lack of education and awareness regarding this phenomenon. Masanja at el has discovered that illiteracy is the main cause of the negativity associated with albinism. An observable shortcoming of this paper is that it failed to show how illiterate people can be educated about albinism as a disorder and not as an illness that brings good or bad luck. This is because the paper illustrated that illiteracy is the main cause of the superstitions and myths, due to the fact that people lack insight and understandings. The question that this journal article interrogates is: how can educating people and bringing awareness on albinism decrease the killings and labelling of people with albinism? The authors should have included a method of resolving the matter at hand.

Cruz-Inigo et al. (2011) wrote a journal article on campaigns and the education of albinism as a disorder. The journal article is about the “various organizations dedicated to increasing albinism awareness and assisting PWA in attaining proper medical care and appropriate

sun protection have been established throughout the world”. They specifically talk about the campaigns in Tanzania, where they have a clinic that educates and helps families and people with albinism to take care of their skin as well as educating them about the risks of not using skin protection. This clinic is aimed at skin cancer screening, public education, and judgmental stigmas. Regarding the causes and killings of people living with albinism, they observed that “traditional midwives may sometimes kill albino children and the case is then presented as still born. Such evidence highlights the prevalence of severe stigmas and misconception associated with albinism and the need for improvement” (Cruz-Inigo et al. 2011:80). This was usually done to protect the mother from stigmas and the shame that having a child with albinism would bring to a family.

## **2.8 African traditional beliefs associated with albinism**

A few scholars have written about the different beliefs associated with albinism. For example, Bradbury-Jones (2018: 8) did a study as a means to find out from people their perceptions on albinism. The study had an equal amount of people who are living with albinism and people without albinism. Some of the people in this study shared that they were taught to believe that when someone who is HIV and AIDS positive has sexual intercourse with a person living with albinism they will be cured of the virus (2018: 8). Bila et al. (2015: 02) in similar vein, adds that people living with albinism get raped often because people think that sleeping with a person with albinism cures one’s HIV and AIDS infection. In addition to the above, Barker et al. (2010: 172) and Machoko (2013: 319) also confirm that people with albinism are attacked and raped because they are used as a means of curing others from HIV and AIDS. This includes people with diabetes, HIV and AIDS, and cancer. This is as a result of the belief that PWA are supernatural or have supernatural powers.

Dapi (2018: 12), lists some of the myths associated with albinism as follows: they are thought to be ghosts (see also Cruz-Ingo 2011: 81): if you give birth to an albino it means you have slept with a white man (see also Barker et al. 2010: 172 and Cruz-Ingo 2011: 81): they are a curse: you are being punished by God when you have a child with albinism ( see also Barker et al. 2010: 172): body parts of people living with albinism are good when making potions to enrich someone (see also Cruz-Ingo 2011: 81). Barker et al. (2010: 172)

adds that in some parts of Africa, it is believed that when someone gives birth to a child with albinism it means that the woman slept with a *tokoloshe*. Generally, a *tokoloshe* is an animal used for Witchcrafts, which is usually sent to do evil to others. In traditional Africa there is a belief that to give birth to a child with albinism means the woman slept with a white person was popular. In this sense, it was believed that the women were punished for sleeping with the white man and this was Gods way to expose these women. The above beliefs include some beliefs about albinism that have led to a negative perception about this disorder.

Bila et al. (2015: 2) adds that people believe that drinking the blood of a person with albinism gives a person magical power. In addition, Cruz-Ingo (2011: 81) held that some people believe that the body parts of PWA are necessary for witchdoctors to make potions. Similarly, Imafidon describes some of the terms that are used to refer to people living with albinism. He states that “among the Yoruba, they [people with albinism] are called *afin*, which means horrible, and in Zimbabwe they are called *sope*, which means someone who is possessed with evil spirit, in South Africa, *isishawa* which means cursed” (Imafidon 2017: 47). This shows that people living with albinism are generally not regarded as human beings.

The chairperson of the albinism society in South Africa (ASSA) Nomasonto Mazibuko, who is also living with albinism, while speaking during an interview with SABC 2 news team in 2018 said that the language used to refer to people living with albinism is a problem. The fact that they are being referred to as “it” gives them less value as human beings thus, they are not respected as human beings.<sup>1</sup>

It must be noted that, out of all the beliefs noted above, majority of the beliefs show that albinism is perceived as something that is bad or rather negative. Even for those who believe that albinism is something positive, they sometimes do so because they wish to use their body parts to make *muthi* to enrich themselves. See appendix one for a full story of a

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<sup>1</sup> See the interview on <https://www.youtube.com/watch?v=xdG73T3hInE> accessed on the 21 July 2019

13-year-old girl who was killed because it was believed that her body parts will make a man's business flourish.

## **2.9 Alvis Imafidon on albinism**

When seeking to find an in-depth understanding about this phenomenon, the work of Alvis Imafidon (2018), who is himself living with albinism, cannot be overlooked due to the important philosophical insights it provides; In his book titled *African philosophy and the otherness of Albinism*, he explains why people with albinism are excluded in the African community. He writes about the acquisition of knowledge in African traditional societies and their ontology, and recommends, among other things, that governments should make means to ensure that the community has a better understanding of albinism.

Alvis Imafidon explains why people living with albinism are not accepted or seen as part of the community. He illustrates how the misconception about this disorder has resulted in stigmas and myths associated with albinism. He also places emphasis on the language that the community uses towards people with albinism and avows that this is as a result of the community lacking knowledge about albinism in general. He asserts that “knowledge about albinism in African traditional and modern societies is damaged with systematic ignorance and falsehood that continue to serve as a veil that hinders the actual facts about albinism” (Imafidon 2018: 71). This book further explains that people living with albinism are seen as a threat to harmony and they are also perceived as harmful beings (Imafidon 2018: 81). One can therefore assume that people with albinism are killed because the community needs to feel safe, but most importantly wants to live in harmony see also Elvis Imafidon 2017.

Imafidon also defines albinism as a genetically inherited disorder, (see also Ester Hongs, 2006: 06; Nontobeko Bila et al. 2015: 01; Stine Braanthen & Benedict Ingstad 2006: 600). He asserts that this book emerges as a reaction primarily to the normative conceptions of albinism (Imafidon 2018: 9). This chapter explores and describes the biological and scientific facts about albinism and the reasons why it is considered a form of disability.

He describes albinism as a condition that affects living things, be it animals or human beings. This condition is as a result of a lack in normal pigmentation. People with albinism



appear to visibly different from others of their own kind (2017: 9). He, similarly, describes albinism as Ester Hongs, (2006: 06), Nontobeko Bila et al. (2015: 01); Stine Braanthen and Benedict Ingstad (2006: 600).

Imafidon is seeking to find out the basis upon which one can describe albinism as a disability. Describing albinism as “a highly and an essentially contested concept in disability studies”. He avows that a disability is an impairment present from birth. This results in one not being able to or having difficulties in doing things that other people may consider to be normal. (Imafidon 2018: 14). He claims that disability is bound to affect everyone at some point in life, either temporarily or permanently. He states that there are some reasons as to why people with albinism can be considered as with disability. The first reason he states is that people living with albinism suffer from visual impairment which results in them having difficulties when engaged in activities such as reading and driving (2018:16). People with albinism should not be exposed to sunlight. Therefore, it is advisable for them to work under conditions where there is little exposure to the sunlight. This includes work such as; farming or construction.

According to Imafidon, PWA (2018) face participation restriction with regards to employment, this is because PWA are discriminated against as a result of cultural and social misinterpretation. The way society perceives them has a great impact on their lives.

The term thick concept can be used to describe any concept that has both descriptive and evaluative dimensions. The description of this concept is embedded in the biological features while the evaluative is embedded in social representation of albinism in the African context. One’s social representation determines a lot of things, for example, how the person is treated, which rights they have, and their lived experience in general (Imafidon 2018: 18).

Describing and exposing the experience of persons with albinism in Africa, Imafidon asserts that “broadly construed, albinism is socially and culturally represented as an unwelcomed abnormality or difference, much the same way as other forms of disability are negatively designated in African tradition” (2018: 19). This seems to suggest that African

traditional people have negative attitude to things that they are not familiar with or something that is different from the norm.

Ontology is the theory of being from the Greek words *ont* (being) and *logos* (theory, discourse or study). According to Imafidon (2018: 28), “ontology relativity implies that context, place and language are essential in formulating a theory of being”. The third chapter of Imafidons book is an attempt to develop general features for one to be considered a being in the African thought system. This helps to know how PWA are understood in African thought. The understanding and misconceptions of albinism seem to be similar in African traditional communities. The difference is in the language used in a particular area. For example, it may be common that people with albinism are perceived as a curse, while in some areas they are considered as animals, but it varies from the type of animal they are called.

Imafidon describes categories of being in African tradition but in connection to albinism emphasis will be on what he calls “queer beings”. He describes “queer” as something that is a variance with what is usual or normal if it differs in some odd or strange way with what is ordinary (Imafidon 2018: 38). Queer of being in African ontology is a being who is visibly human but may lack some qualities. Hence, queer beings may look like human, but they are not regarded as human or treated as humans in African traditional society (2018: 18). All persons with albinism have characteristics of being human except for the pigmentation, hence, they are excluded from the category of being. In African societies PWA are perceived as different and unusual resulting in their stigmatization.

A person with albinism is regarded as “a human other”, something different from the approved and accepted notion of a human being. The result is that they are unable to participate or being part of certain groups or engage in certain social activities.

Imafidon (2017) explains why people living with albinism suffer from social exclusion. He argues that people living with albinism are ill-treated because they are perceived as the other. He avows that people living with albinism are an ontological other in the African community of being. This means that their physical appearance makes the community see them as different, hence, the community cannot relate to them as fellow humans. People

living with albinism are excluded from the community because they are different in nature. In addition, he affirms that “Africans are unable to cope with, and, unwilling to accept anything that is different or unusual from the status quo” (Imafidon 2018: 165). Imafidon shows “how African communities have managed to establish and promote ontological normative ideologies that help to sustain the ill-treatment of people living with albinism”. He asserts that people living with albinism are an ontological other in African communities of being, which explains why there are stigmas surrounding this disorder. When he refers to otherness, he refers “to the quality of being different, unusual and alien from the conscious self or a cultural orientation” (Imafidon 2018: 165). African ontology isolates the other being due to their unusual nature, hence, they are treated as the other, resulting in exclusion from the community.

He attempts to understand how one can get knowledge about albinism. He makes use of three levels in which he claims that an African can claim to know anything. This will be discussed below.

The epistemological section of the book shows that knowledge about albinism in traditional African and modern societies is, according to Imafidon, “riddled with systemic ignorance and falsehood that continue to serve as a mask that hinders the facts about albinism” (Imafidon 2017:71). He further shows that the untruths about albinism “are part of a consistent and reliable set of beliefs that are not only deeply entrenched in African thought systems, cherished and shared by Africans, but are seen as providing functional explanations for objects and events”. He explains that the lack of knowledge about albinism is as a result of the ill-treatment and stigmas associated with albinism. He describes what he calls the three levels which an African can claim to know anything. According to Imafidon, knowledge is gained through being told, shared knowledge and consistent beliefs. Which means that what we know about albinism is what we have been told by someone close, it is something that we believe in as a group. Imafidon attempts to understand the knowledge about albinism.

Imafidon states that an African knows what they know through what they have personally sensed or experienced, and they have no doubt about it (Imafidon 2018: 53). This means that in most cases, what people might know from a friend, a friend that seems to be sure

about the knowledge that they are sharing, will be knowledge gained at first hand. For example, people have information about what they know about albinism because they have been told by a close person, be it a friend or family member.

Imafidon emphasizes that people gain knowledge consistently. For instance, people will familiarize themselves about a certain phenomenon and share beliefs about it then the beliefs become norms. Due to the lack of understanding about albinism, people made their own meanings about the disorder hence people established different beliefs which has fallen from generation to generation hence people associate this disorder with these beliefs. In recent times, there has been research done by way of finding the meaning and causes of albinism. Authors such as, Ester Hongs (2006: 06), Nontobeko Bila et al. (2015: 01), and Stine Braanthen and Benedict Ingstad (2006: 600) have defined albinism as basically a disorder that affects the pigmentation of the eye, hair or and eye brows of a person. Even with this establishment, African traditional beliefs on albinism are still negative towards people with albinism. This point goes to show that it is challenging to change people's established beliefs and perceptions.

Imafidon avows that “what I know is what we know”- see Imafidon 2018: 61. In this level of knowing in African traditions, knowledge claims about albinism are, thus, shared. This means that Africans attain knowledge through sharing. For example, in African indigenous knowledge, one learns that in most cases knowledge is shared by adults of a group, sharing it with the younger generation. In connection with albinism, it is evident that in the past, the older generation thought the younger ones about the beliefs that are known about albinism. I remember when we were growing up, we were told by the elderly that playing with a PWA will bring bad luck to the family. This is the reason why at some point we did not want to associate ourselves with people living with albinism, that is, to protect our family from any form of bad luck.

The above section has proven that in African traditional communities, one attains knowledge through the community. One can assert that it is through social interaction that one gains knowledge. Thus, it can be argued that, how one perceives PWA has an effect on how they are treated.

PWA are living in fear of being killed or attacked for their body parts due to the myths and superstitions surrounding albinism. In a similar vein, Salewi (2011) and Mswela (2017) asserted that people living with albinism are killed and attacked because of the misconception about the disorder. Which has also led to them being unable to continue living like ordinary citizens in the country. In a similar vein, in September 2018, a television series called *Uzalo* in South Africa, shown on channel SABC 1 aired as a means of doing an awareness campaign against the killings and attacks of PWA. This series highlighted some of the struggles and difficulties that PWA go through. The series, which portrayed a family with a teenager living with albinism, demonstrated that people living with albinism are living in fear. Every time the girl had to go to school, her parents feared that she may not come back home. The family went as far as having someone go with her to school. It also revealed that some family members of persons living with albinism would want to sacrifice the person with albinism for their wealth. In this television series, the uncle of the girl with albinism was the person that abducted her from her home. He had planned with a *sangoma* to kill the girl and use her for rituals that would make him rich. This also confirms some of the myths which lead people living with albinism to live in fear.

Imafidon has explored some of the socially constructed essence of albinism that have been deeply waxed into African societies, which have had and continues to have terrible consequences for PWA.

The last section of Imafidon's book examines the issues and challenges that are faced by PWA. This chapter in no way exhausts the issues faced by people living with albinism, but rather, it attempts to point readers to the part of the discourse to focus on. But the issues examined in the last chapters show very clearly that PWA are in a risky and unfair situation. Imafidon (2018: 92) affirms that, "they [people with albinism] live in societies without justice and fairness". He asserts "that systems in the society are structured in ways that immensely diminish their self-worth and dignity". The last chapter of Imafidon's book also makes it clear that a very minimal amount of people living with albinism succeed in overcoming the prejudices against them and can make meaning out of their socially condemned existence.

## **2.10 Reported cases on attacks and the killings of PWA**

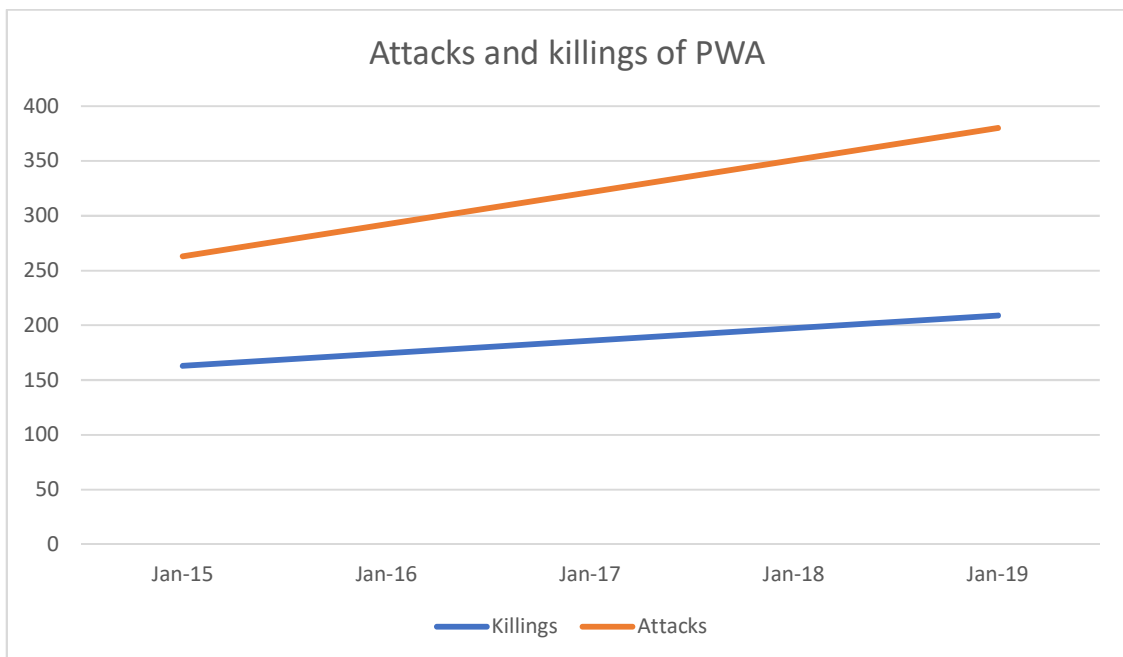
### **2.10.1 Under The Same Sun Report**

Under the Same Sun is an African NGO that aims at bettering the life of PWA. Under The Same Sun, commonly known as UTSS, “is a Christian charitable organization that promotes the wellbeing of persons with albinism (PWA) via education and advocacy”. They help people with albinism “overcome, often, deadly discrimination through education and advocacy”. In many parts of Africa, people with albinism are misunderstood, mistreated and even attacked or killed. The Advocacy and Public Awareness Program educates people on the truths about albinism and makes a case for the inclusion of the human rights of people with albinism. “I have a dream that one day people with albinism will take their rightful place throughout every level of society, and that the days of discrimination against persons with albinism will be a faint memory” says Peter Ash - Founder & CEO of Under The Same Sun NGO.

The report publicized by Under the Same Sun in May 2019 confirms that “many attacks and killings of PWA in Africa are not documented or reported”. UTSS is “certain that crimes of color against PWA are common in various parts of almost all African countries. Most myths reduce PWA to ghosts, magical beings or curses, etc. On rare occasions, the discrimination is reversed and the PWA are “deified” into “Gods”. Either way, they rarely get to enjoy their status as normal human beings” (UTSS report 2019:1). Many countries have stories about the mysterious disappearance of PWA. There is a growing, documented truth to these rumors. UTSS confirmed “We know that many PWA have “disappeared” due to abduction, then mutilated and killed by fellow citizens (sometimes family members, friends or neighbors) for the purpose of witchcraft related rituals” (UTSS report 2019: 1). In addition, the NGO confirmed that “These ritual attacks, which regularly find their roots in ancient ancestral beliefs, are a familiar concept to most Africans, and have been going on for a very long time” (UTSS report 2019: 1). This is evidence that the African traditional beliefs surrounding albinism have been known and kept in the African communities for a long time.

Cited from the report published in 2019 by Under The Same Sun, “Countries known to be involved in the cross-border trade of PWA and their body parts: Tanzania, Burundi, Kenya, DRC, Mozambique, Malawi, South Africa, Swaziland” (UTSS report 2019 :1). Below is a graph to demonstrate the increase of the attacks and killings towards people with albinism

UTSS have found partners to assist them to get data from its own field research, which makes it possible for the NGO to publish reports. They have confirmed that the record cases that have been verified thoroughly. However, getting the exact number of people living with albinism that are attacked is not always possible because it is not all the cases that get to be reported to the police. However, the NGO makes means of getting as many cases to record as possible, they record cases from associates, mass media and public institutions that are reasonable and credible.



Graph 2.1 This graph is my own interpretation of the report from Under the Same Sun.

The above chart is a brief summary of the reports from Under the Same Sun., The reports were done between December 2015 and January 2019. The reports show that there is an increase in the amount of reported cases of attacks and killings against people with

albinism. It was also made clear that these reports only included the documented incidents of attacks or killing of people living with albinism. When analyzing the above reports, it is evident that within the space of three years, there has been an increase of 163 reported cases the attacks and killings of people living with albinism.

Appendix three presents the full reports of the cases of attacks and killings of PWA provided by the UTSS NGO.

### **2.10.2 The case of Gabisile Shabangu in South Africa**

In February 2018, a 13-year-old Gabisile Shabane was abducted from her home. The 13-year-old Gabisile, who was living with albinism, was found almost after a month of being missing. Her body was found in a shallow grave with some of her body parts missing. It was later discovered that the 28-year-old man, who was arrested for her murder, was sent by a *Sangoma* to get body parts of any albino to make his business flourish (ANA reporter 2018:1). The South African Albinism Society chairperson, Mrs. Nomasonto Mazibuko, who was interviewed on SABC news in February 2018 in relation to the increasing number of people living with albinism, affirms that “language is still a problem, many people who have this disorder or condition are called “it””. Hence, they are not valued or respected for their humanity (SABC news interview between lee-Ann and Nomasonto Mazibuko, watch the following link found on YouTube, <https://www.youtube.com/watch?v=xdG73T3hInE>)

In August 2019, an article was published by the Citi newsroom, a Ghanaian news website. The article was a follow-up on the above-mentioned case. The most recent update about this story was that Gabisile was killed by a man who was a professional teacher. The 40-year-old man admitted to killing Gabisile for a ritual referred to as *muthi*. This is because it is believed that the body parts of people living with albinism can be used to make good *muthi*. He pleaded guilty and apologized to the people affected. Speaking after the hearing, Gabisiles mother tearfully related how she still has images of her daughters’ headless body, with some of her other body parts missing. She added that the family is afraid that they will be attacked again to get the second child. She asserted that they need to make sure that there are extra security measures because she fears that her other daughter will be the next



victim. She further added that her sister is suffering psychologically because her 10-month-old son was brutally killed by these men. An arrest was made of four men who were involved in this killing. (Citi newsroom August 23, 2019). The above story is the sad reality of people living with albinism. The above indicates two issues experienced by the family, which are, psychological issues and living in fear.

### **2.11 The Zulu kings' perception on the attacks and killings of PWA**

It is important that the study includes The Zulu King's perspective on albinism. This is because Kings in African communities have immense influence in the community. They are well respected, and their views are valued. According to (Mthandeni 92: 1) "A chief or traditional leader is defined as an individual who, by virtue of his or her ancestry, occupies a stool of an area, and this person has been appointed to it in accordance with the traditions and customs of the area". This person has traditional authority over the people who live in that area (Mthandeni 92: 1). A chief is further defined as "a traditional leader of a specific traditional community who exercises authority over a number of headmen in accordance with customary law, or within whose area of jurisdiction a number of headmen exercise authority" (Bizana-Tutu 2008: 6). They are responsible for maintaining order and peace in the community as well as solving any disputes that arise in the community.

The Zulu King, Goodwill Zwelithini, "has spoken against traditional healers who use body parts of albinos" (Khomu 2016: 1). He also vowed to go the extra mile to ensure albinos feel safe in KZN. He mentioned that "Traditional healing is part of our culture as the Zulu nation and we believe it is a gift from our late forefathers" (Khomu, 2016: 1). He continued to state that, "It has forever been part of the Zulu nation's culture. I find it an insult to our culture that some people hunt albinos as if they are animals. Our forefathers never killed anyone for *muthi*" (khomo 2016: 1). Speaking at the Ondini Cultural Museum near Ulundi, the king said, "he would like to have a record of all albinos to make it easier to look for them if they suddenly disappeared". *Appendix 2* is the full article.

### **2.12 Muthi killings in relation to the killings of people living with albinism**

People living with albinism are commonly killed for rituals. As noted above the Zulu King lashed out at traditional healers because some traditional healers believe that the body parts

of persons living with albinism can be used to make *muthi* that will bring luck to people. In Africa, ritual murder has been widespread among societies. Ritual or *muthi* murders are a form of human sacrifice practiced by some African tribes (Munthali 2005: 29). There are strong indications that some tribes still use human body parts as ingredients in the traditional medicine because of the belief that it will make strong *muthi*. Among African societies, ritual murders involve removing the required body parts from the victim while the person is still alive (Labuschagne 2014: 191-206). Such actions make one to question the African ideal of living in solidarity or in harmony with others. It also makes one to wonder whether the African community is becoming so individualistic that there is no care for the pain inflicted on others. It does appear that what matters to people now is their own self-enhancement over another person's life.

The aim of such *muthi* killings is mainly to acquire human body parts for ingredients to make certain potions. Majority of the time, this type of killing occurs when people believe that they will attain certain powers from the *muthi* that is made of body parts. According to an article called *Persons with albinism killed for muthi*. The Under the Same Sun Report confirmed that the use of the body parts of people with albinism for *muthi* is part of a larger practice in the use of human body parts for *muthi*. People with albinism are killed for many reasons, some of which include, the abstractions of their body parts to make *muthi* that will enrich others. To cite an example of such a case is the story of the 13-year-old girl Gabisile, who was living with albinism and was killed with the belief that her body parts will enrich a businessman. *Appendix 1* has the full article of Gabisile's story

### **2.13 Defining a person from an African perspective**

It is important to seek clarity as to who is a person or what constitutes to be a person in the African context. This is because one might argue that the attacks, myths, and superstitions surrounding albinism is as a result of the belief that PWA are not persons. People normally question what they do not perceive to be a norm, what they see as abnormal, or unusual and try to find reasonings for such unusual things. They find explanations for it, as a result, there are questions as to whether PWA are persons or not.

Imafidon (2017), explains why people living with albinism suffer from social exclusion. He argues that people living with albinism are ill-treated because they are perceived as the other. He avows that people living with albinism are an ontological other in the African community of being. This means that their physical appearance makes the community to see them as different, hence, the community cannot relate to them as fellow humans. People living with albinism are excluded from the community because they are different in nature. In addition, he confirms that “Africans are unable to cope with, and, unwilling to accept anything that is different or unusual from the status quo” (Imafidon 2017: 165). This is because African people are usually into stereotyping and find it difficult to learn something new.

Imafidon explains how the “African community has managed to establish and promote ontological normative ideologies that help to sustain the ill-treatment of people living with albinism” (2017: 165). He asserts that “people living with albinism are an ontological other in the African community of being, which explains why there are stigmas surrounding this disorder”. When he refers to otherness, he refers “to the quality of being different, unusual and alien from the conscious self or a cultural orientation” (Imafidon 2017: 165). It can be therefore concluded that the African ontology separates people living with albinism due to their rare nature, hence, they are treated as the other, resulting in exclusion from the community.

With regards to this research, the study investigates the nature of a person from an African perspective. This is because the study thinks it best to understand the personhood ascribed to people living with albinism before analysing the beliefs surrounding them. The study limits itself with the Akan and Yoruba conceptual schemes of a person since they are the most referred to in the literature

### **2.13.1 The Akan schemes**

According to Appiah (2004), the Akans have three different concepts of what makes a person. Matolino (2014: 92) citing Appiah, argues that the conception of what makes a

person includes “The body, *Nipadua*, the *Sunsum*, which he calls an individual spirit, and the *Okra*, which is seen as a life force that is given by the creator to every individual when they are born” In a similar vein, Wiredu (1980: 47) concurs that for the Akans, a person constitutes of a body which is the *Nipadua*, but also adds the following combination of units considered as spiritual elements ;1) *Okra*, 2) *Sunsum*. What is different from Appiah’s conception is the 3) *Ntoro*, a thing which is passed down from the father, which is the basis of an inherited characteristics and 4) *Mogya*, which is similar to *ntoro* but this time passed down from the mothers side which is said to determine the clan and identity of a man.

### **2.13.2 The Yoruba scheme**

Segun Gbadegesin (1991) claim that there are two meaning of the concept of a person, according to this scheme. He named the two conceptions as normative and the ordinary. In his argument he emphasised the normative meaning. He identified four elements of the constituents of personhood for the Yoruba, namely; “*Okan, emi, orib* and *ara*” (1991: 28). He describes them as follows: “the *okan* as the emotions and consciousness of beings, the *emi*, is the principle of life” (1991: 33) “the *orib*, which is the human head” and the *ara*, which is the human organs and his actual physic. (1991: 28). According to Brown (2004: 162), both the Akan and the Yoruba schemes similarly avow that a human or a person is a combination of the body and the spirit and without either there is nothing to be considered as a person.

With the evidence from the above philosophers and schemes, one can say that in, or, from an African viewpoint, PWA can and should be considered persons who has the rights of being considered a person.

### **2.14 The meaning and values embedded on Ubuntu**

Ubuntu directly translates to humanness and it refers to the way African people should live their lives, which includes treating others with equality and valuing human dignity( Murove :2016). This should include everyone irrespective of their status in a society. According to Felix Murove:

The African concept of Ubuntu is based on the idea that human beings are originally beings in relationships. The dominant understanding here is that as human beings we depend on other human beings for our flourishing. It is on the basis of existential reality of our dependence and interdependence with each other that we recognise each other as mutually belonging. Our humanness is thus dovetailed with the assertion that being human is our existential precondition to our boundedness with others (Murove 2016: 172).

What Murove means here is that humans depend on each other for their flourishing rather than use people to flourish, like what some people do to people with albinism. A person experiences a sense of self-respect and value by the way she/he is treated by others. In a similar vein, the idiom *Umuntu ngumuntu ngabantu*, is a well-known and commonly used phrase by Africans, which directly translates as ‘a person is person’ through other people. Even though our society is becoming individualistic, one cannot survive or live alone. African communities are said to be communitarian because African people value unity. For example, the maxim, *it takes a village to raise a child*. This African maxim is an indication that someone’s journey in life does not only depend on the family but also on the community.

According to Kamwangumalu (1999: 25-26 as cited in Murove 2016: 175), “Ubuntu is a multidimensional concept which represents the core values of African ontologies; respect for any human being, for human dignity, for human life, collective sharedness, obedience, humility, solidarity, hospitality, interdependence, communalism, to mention a few”. In addition, Mluleki Munyaka and Mokgethi Molhab (as cited in Murove 2009: 68) assert that:

In the African world view, the community is the context for the manifestation of both *umuntu* and *ubuntu*. The value and dignity of a person is the best realised in the relationship with others. One cannot be a human being alone, only in a community. An African individual is a communal being, inseparable

from and incomplete without others, everyone belongs and there is no one who does not belong.

In a discussion of ubuntu, Sivhanga Netshitombani also discuss the sources of Ubuntu, he says that:

The main source of *ubuntu* are idioms which set down norms which every member of the community is expected to conform to. Well known amongst them is *Umntu ngumuntu ngabantu*. Literally translated it means a person is a person because of what other members of the community have done for him. In short, *ubuntu* signifies the centrality and the importance of an individual's interdependence with other members of the community (Netshitombani 1998: 14).

Ubuntu has been explained from a philosophical perspective, in which it recognizes that people should be treated with respect for their humanity. This encourages the members of a community to be kind, caring, sympathetic, and accepting to fellow human beings. The question that arises with regards to this study is why to some South Africans continue in attacking, killing, and stigmatizing people living with albinism. One might question whether the spirit of ubuntu no longer exists for the African people. The study agrees with Pityana when he stated that moral virtues, obligations and values have changed with time. He writes:

The changing moral rules may not always be noticeable. They change even as those who abide by them insist, they are conservative. It is only that they do not notice. When they get noticed, there may be resistance. The very nature of morality, therefore, is that it is conservative because it seeks to preserve the structure of society. (Pityana 1999: 142)

The quotation above is an assurance of the changes in African communities, even though people might insist that they are still traditional, and that modernity does not influence them. The reality is that it does. Modernity has affected this phenomenon even though the traditional people still claim that modernity does not influence them. The following is a brief explanation. Modern *lobola* (ilobola is called bride price in English, it is a practice

by most African cultures, where a man who has a wish to marry a woman pays money to her family as means to show appreciation for raising the woman) is more about money rather than building a relationship between families. The woman's family wants money as if they are selling their daughter. They want money because she had the best education and that she is a professional, whereas a man will expect the woman to abide by all that he says because he paid *lobola* or he has 'bought his wife'. The significance of such a practice has been lost, this practice is done to bring two families together. It is evident that modernity has affected our perceptions and the way we do things compared to our traditional way.

### **2.15 The statistics of killings and attacks of people living with albinism in S.A**

The beliefs discussed in the section of beliefs surrounding albinism have resulted in killings, attacks, the stigmatization, and misconceptions surrounding albinism. The Under the Same Sun NGO conducted a research as a means of getting statistics on the number of people living with albinism that are affected by attacks and ill-treatment of which is heard on the news and in the communities. Thus far, the NGO has published three reports in 2013, 2015 and 2019.

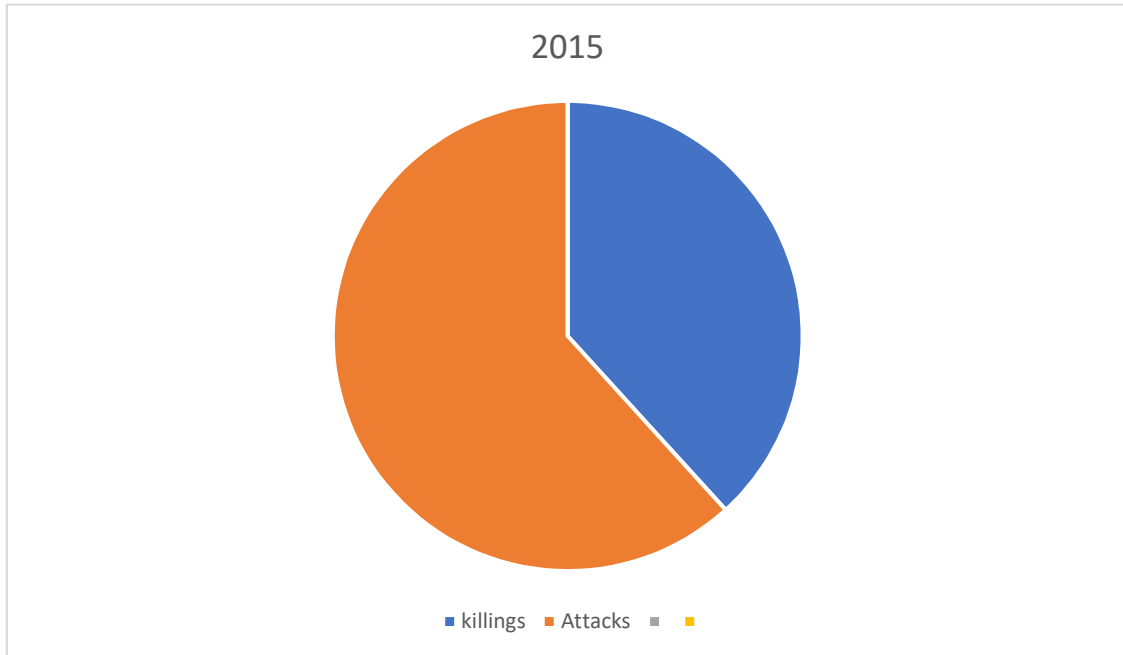
#### **2.15.1 The Under The Same Sun report for 2013**

The full reports are attached in the appendix. The reports show that in 2013, Tanzania has the largest number of cases reported. Among the 124 reported cases, 72 were killings, 35 were survivors but mostly with severe mutilations, 15 were grave robberies, and 2 were attempted grave robberies. In all the reports, Tanzania has the largest amount of reported cases. In the case of South Africa three cases were reported in 2013. This was one killing, one missing person, and one grave robbery.

#### **2.15.2 The Under The Same Sun report for 2015**

It must be noted that this report does not consist of all the cases against PWA for the year, but this NGO has based the provided information on cases that have been reported. It is important that we note the increase in the number of cases reported compared to the previous report which is the 2013 report. In this report, a total of 25 countries were included, and from the 25 countries a total of 426 cases were reported. The report shows that 263 people were attacked. This includes violence, rape, attempted abduction, people

who went missing, and grave violations. Out of the 426 cases, 163 were reported cases of people who were killed.

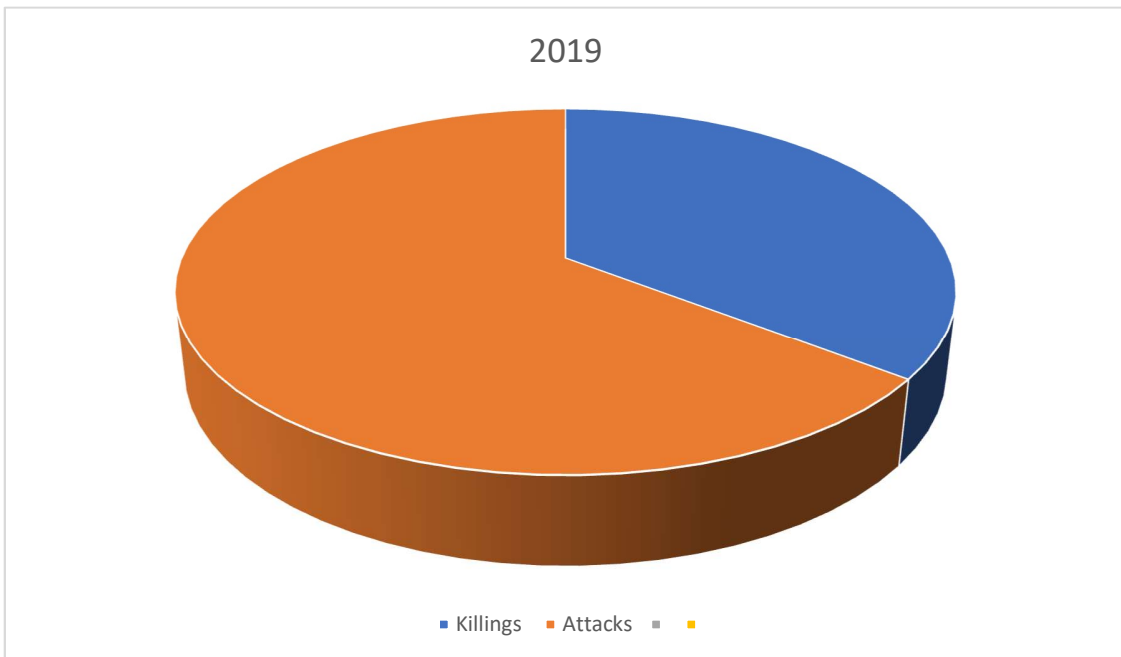


Graph 2.2. This is the study’s interpretation of the statics from the Under the Same Sun report published in 2015, for cases that were reported against people living with albinism in 25 countries.

### 2.15.3 The Under The Same Sun report for 2019

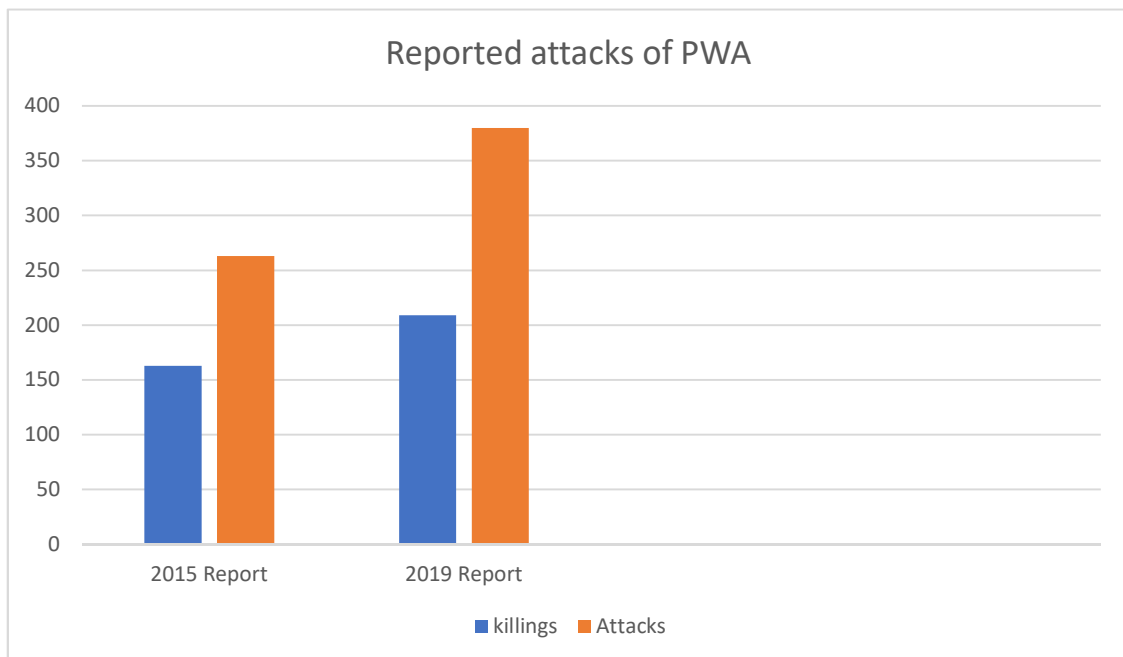
The 2019 report shows yet again an increase compared to the above report. From this report, there are 30 countries that were assessed. The total amount of cases reported summed up to 589. This includes 380 of the attacks which includes asylum, refuge cases, violence, rape, attempted abduction, survivors of mutilation as well as grave violence. Out of the 589, 209 were reports of people who were killed.





Graph 2.3. The above graph is the study’s interpretation of the 2019 report published by Under the Same Sun NGO, of attacks and killings of people.

The graph below is a summary of both figure two and figure three. It shows a clear comparison between the two reports. The chart below is a brief summary of the reports from Under the Same Sun. The reports were compiled between December 2015 and January 2019. The reports show that there is an increase in the amount of reported cases of attacks and killings against people with albinism. It was also made clear that these reports only included the documented incidents. When analyzing the above reports, it is evident that within the space of three years, there has been an increase of 163 reported cases. Which includes 46 increases in the killings and 117 of the attacks ( UTSS 2019:01).In the Appendix the full reports are attached.



Graph 2.4 is the study’s own interpretation of the information obtained from the Under the Same Sun Reports. The Appendix will attach the three reports, (UTSS 2013, 2015,2019).

### **2.16 The social Construct of reality**

Social construct is the idea that knowledge that exist is not an objective reality but rather it is a result of human action. Thus, things that exist are as a result of humans coming together and agreeing that such things exist. Alexandra Galbin (2014: 82) asserts that “Social Constructionism or the social construction of reality is a theory of knowledge of sociology and communication that examines the development jointly constructed understanding of the world”. This means that knowledge is attained by one’s interaction with others. In addition, Gergen (1985: 265 as cited in Galbin 2014: 82) claims that “Social constructionism may be defined as a perspective which believes that a great deal of human life exists as it does due to social and interpersonal influences”. In connection to the phenomena discussed in this study, the study suggests that the myths and superstitions surrounding albinism are as a result of knowledge that has been shared by people.

Therefore, the beliefs surrounding this phenomenon is through human interaction, which has led to the reality faced by PWA.

### **2.17 African customary Law**

It is important to briefly explain how legal matters were addressed in African traditional communities since we are analyzing an African traditional phenomenon. South Africa is a multicultural society, hence, there are people from different cultures, and these cultures are grounded in laws and principles that members of a community ought to abide by. In traditional Africa, there were no formal or professional lawyers. As such, it was the duty of community leaders as well as the elders of a community to resolve disputes (Rautenbanch 2018: 26). African customary laws are the African indigenous laws that governed African people. It is unfortunate that these laws cannot be traced, this is because African people never documented information but rather information was passed down from generation to generation, hence, we do not have anything tangible to refer to. Typically, disputes are resolved in a courtroom. For Africans, especially in the rural areas, this courtroom is in a royal home where the Kings and Chiefs solve matters and give judgements. In contemporary Africa, such laws are respected and are highly valued. This type of law is significant to the study because it is evidence to show that African traditional communities were governed by a law even before the Universal declaration of Human Rights and the Bill of Rights.

### **2.18 The Gap in Literature**

It is evident from the above literature that scholars have written about albinism from different perspectives and disciplines. Many scholars have written articles from the legal perspective, as a means of advocating for the rights of PWA. This study is looking at this phenomenon from an ethical perspective through the lens of the ethical theory of limited communitarianism. From the above scholars, it has been noted that the killings, attacks and stigmatization of PWA is due to the beliefs surrounding the disorder. The current study

analyzes the African traditional beliefs surrounding albinism through the lens of limited communitarianism.

### **2.19 Conclusion**

This chapter has outlined the literature that guides the study. The chapter surveyed books, journals, and articles that are relevant guides for the study. The key issue noted in this chapter is that people living with albinism are killed for two main reasons: where some believe that they bring good luck and that they are a special type of people and where some believe that they cause bad luck. Regardless of people's perceptions on albinism, people living with albinism in South Africa do not seem to have any rights in their communities, hence, majority of the above scholars advocate for their rights, at least basic human rights. It must be noted that the community's perception of someone or someone's illness has a major impact on the person's life. In contrast, the African community and the values of this community clearly shows that all human beings should be valued and treated with dignity. As noted above, Africans believe in unity, hence, one cannot live without other people.

The next chapter is chapter three. Chapter three is the theoretical framework. This chapter will introduce the theory that is used to guide this study to analyze the issues that affect people living with albinism. Thus, the chapter looks at how the communitarian approach analyzes the beliefs of African traditional community concerning albinism. The study intends to analyze the belief from an African context using the communitarian theory. This study focuses on limited communitarianism proposed by Matolino (2014) and the rights-based approach which is closely related to human rights. Both these theories guide the study in showing that people living with albinism have rights and that these rights cannot be violated. The theories are used to challenge the beliefs on albinism. It is also used to prescribe what ought to be done in order to address the beliefs of people living with albinism.

## **Chapter three – Theoretical framework**

### **3.0 Introduction**

*In African communal tradition, 'personhood' does not just describe a human being with body and mind but also an individual who indicates by his actions that he can accept and meet certain standards of social responsibility to achieve recognition (Ikuenobe 2006: 58).*

The above statement by Ikuenobe is important for this study. It encompasses the theoretical framework that is influential in guiding the study. It asserts that personhood does not describe the physics of a human only. It also includes the way a person carries themselves in a community. In addition, your personhood also includes the way you treat other people in a community.

The previous chapter discussed the literature that guides this research. The purpose of that chapter was to provide insight on albinism. It must be noted that from the previous chapter that scholars have written about this phenomenon from different perspectives, some of which include; the legal or law perspective, social science, anthropology, and philosophy, just to mention. What is important though is the fact that majority of them have written as a means of advocating for the protection of the human rights of PWA. The main scholars whose works were reviewed in the previous chapters are Alvis Imafidon, John Makhumbe, Mswela and Salewi. The current chapter is the theoretical framework. This chapter will discuss the theory that guides the study. The aim of this chapter is to provide a perspective or lens through which to examine the African traditional beliefs surrounding albinism. This

study will make use of two theories namely, limited communitarianism and the rights-based theory.

In an African traditional community, being human does not necessarily mean that one can be considered a person, or, as someone who has attained personhood. But it is believed that one must have certain qualities and must attain certain standards in order to be considered a person. It is therefore important that this study makes use of an African theory that speaks to African communities. Many Africans question the humanity of PWA while some question the African traditional beliefs surrounding albinism. As a result, it is important to examine how the communities perceive albinism and the reasons for these conceptions. Therefore, this study will start by exploring who a person is and what makes a person in the African context. Thereafter, there is a description of how the rights of people living with albinism are infringed upon. The communitarian theory used in this study when analysing African traditional beliefs regarding albinism in South Africa will be also discussed.

### **3.1 Defining Communitarianism**

Arockia Raj (2016: 02), defines the community as a group of people who live in the same place or share certain characteristics. With this definition in mind, the study looks at the meaning of community in the African context. In contrast to the above general definition of a community, for the African people, the community is not just a mere collection of people who live together in the same place. According to Coetzee and Roux (1998: 320 as cited in Murove 2009) the African community consists of:

a group of persons linked by interpersonal bonds, biological and/or non-biological, who consider themselves primarily as members of the group and who have common interests, goals and values. The notion of common interest and values is crucial to an adequate conception of community, the notion in fact defines the community. It is the notion of common interest, goals and values that differentiate a community from a mere association of individual

persons. Members of a community share goals and values. They have intellectual and ideological, as well as emotional, attachment to those goals and values; as long as they cherish them, they are ready to peruse and defend them.

The difference from the above definitions of community is that the first one speaks of people living in a shared space. Whereas, the second one speaks of a group of people who have things in common but most importantly, people who are tied together by certain bonds. This definition is an indication that a community for Africans is not just a living environment but places the important of people in it and the bonds shared by those people. These people share bonds and are attached to one another. Communitarianism refers to a theory that seeks to minimize the emphasis on individual rights and puts an emphasis on shared responsibility. Menkiti (1984: 179-180) is of the view that communitarianism is a “collectivist sense,” which is attached by “organic dimension that holds a relationship between the community and the individuals living there”. In addition, Kenyatta (1965: 180), Senghor (1964: 49:93-94) and Menkiti (1984: 17) similarly assert that in “an African thought the reality of the communal world takes precedence over the reality of the individual life”. This means that in the African understanding, no human being can live their life on their own.

Furthermore, Menkiti (1984: 179-180) sees communitarianism “as a “collectivist sense” which is attached by organic dimension that holds a relationship between the community and the individuals living there”. To ascertain the above claims, Kollman (1988: 59) avows that “African morality and ethics cannot be conceived outside the community”. The above scholars similarly claim that in Africa, the community is perceived as the most important, compared to the individual. In a similar vein, Bujo (1990: 95) states that “in an African setting the individual cannot exist without the community and that the community is the unity of individuals”. According to Bujo, a person living in the African traditional setting, must live in solidarity with other members. He asserts that every individual in the community must contribute to the well-being of others, hence, such individuals are very important in the African traditional setting. Moreover, Masolo (2004:

495), explains that communitarianism “calls for mutual and shared responsibility from everyone. It requires of everyone to realize that they cannot live in a society and be indifferent”. By this, Masolo means that all individuals within a certain space identify themselves in the same way. The ethic of participatory differences requires of everyone an obligation towards those whom they share social space. This means that everyone in a society has the responsibility to ensure that all individuals live harmoniously. In addition to Masolo’s view, Manzini (2017: 04), claims that “communitarianism is an ethic that holds the view that the community’s identity is more important than that of an individual and that the individual should act in ways that will ensure a harmonious society”. He adds that the harmony mentioned above “is achieved if the individual firstly, understands and accepts the communal norms, and that the individual puts these norms first even if it comes at the expense of their own personal harmony”. Communitarianism refers to a theory that seeks to minimize the emphasis on individual rights and puts an emphasis on shared responsibility.

### **3.2 The values imbedded in African communitarianism**

Van der Walt (2003) refers to different authors that have written on the values of African societies. He claims that “in traditional society a shared morality was the cement of society” (Van der Walt 2003: 52). The following list of traditional values have been mentioned by different authors namely, “Ubuntu, Charity, honesty, hospitality, generosity, loyalty, truthfulness, solidarity, and respect for nature, elders and God” (Kinoti, 1992: 84). In addition, Kinoti differentiates personal values, which helped individuals to be united people, such as “honesty, reliability, generosity, courage, temperance, humanity and justice, and social values that helped society to remain integrated, like peace, harmony, respect for authority, respect for and fear of supernatural realities” (Kinoti, 1992: 80). Mojola (1988: 324) also adds to the list and he mentioned “harmony, peace, friendliness and decency”. Besides those mentioned by the above scholars, Gyekye (1998: 324) added the following traditional African virtues: “kindness, compassion, sympathy, concern for others—in short, any action or behaviour that is conducive to the promotion of the welfare of others”. This type of behaviour is taught to an African child from a young age because



they want certain characteristics in an African person. For example, traditional African people respect each other. This is visible in the simplest things like greeting a person.

### **3.3 Communitarian understanding of a person**

#### **3.3.1 Radical communitarianism**

John Mbiti (1970), Placide Tempels (1959) and Ifeanyi Menkiti (1984) are the three classical proponents of radical communitarianism. Bernard Matolino (2014: 71) asserts that radical communitarianism, according to the three above scholars, “believes that African reality is construed by the reality of the community”. According to Radical communitarianism, priority is given to the responsibilities, which individuals have towards the community and the right of individuals are not as important. What is common about the above scholars is the fact that they ascertain that in African tradition, the community takes precedence over the individual. Mbiti avows that an individual has no existence outside the community. In addition, Menkiti (1984: 171), states that “a man is defined in the envioning community”. The above scholars agree that there are processes one needs to go through as a means for being incorporated with or by the community. For example, initiation, among the Nguni tribe, usually found in KwaZulu Natal in SA and the IsiZulu speaking people have a ceremony called *Imbeleko*. This ceremony is done for a new member of a family to welcome him/her into the family and, ancestors and most importantly, introduce this new member to the community. Usually, if this ceremony is not done the child is not recognised by the family and the community. There are different initiation ceremonies among this tribe and all of these ceremonies signify that a person is welcomed into a new stage of life in the community. This is an example of how the community can define who one is in that community. Radical communitarianism is one of the oldest types of communitarianism.

##### **3.3.1.1 Placide Tempels on African communitarianism**

Placide Temple is a well-known and respected philosopher who is one of the fathers of communitarianism. He is well known for his famous article titled the Bantu Philosophy

(1959). The objective of this article is to show that Africans also have a philosophy. He wrote this article to educate and enlighten the Europeans about the Bantu way of life. Matolino (2014: 35) asserts that “Temple wrote primarily for colonial administrators and his main aim was to educate them on the way of life of the Bantu, in particular, they sought to explore the Bantu’s mind and philosophy through a careful analysis of what the Bantu valued the most and how they lived as evidence of value”. His work was rejected by many scholars including Gyekye, even though scholars such as John Mbiti have constructed their arguments on Temple’s understanding of personhood.

In Tempel’s conceptualisation of a person, he argues that Bantu people are a living force. He ascertains that for the Bantu the human being is a supreme living force, which was created by God to be the most powerful among all other created creatures. Tempel (1959) argues for the foregoing because he believes that God created humans to have precedence over any other living creature, including animals and plants. One can argue and say that it is therefore acceptable for human beings to eat plants and animals, and this cannot be the other way round.

For Temple, “Bantu people, as a vital force, need to be engaged in relation with his surrounding environment, fellow humans and inanimate things” (Tempel 1959: 67). A practical example for this would be a person who takes care of their environment, respecting others, living in solidarity with other human beings and valuing norms of the community. Tempel asserts that “it is by this interaction that the Bantu people find their place and space in the communitarian society” (1959: 67). In his thesis, Tempel also discusses that it is important that one follows rules and achieve moral worth in order to be recognised as a person. As a result, people who fail to follow rules and carry themselves as moral beings do not get to be called persons.

### ***3.3.1.2 John Mbiti***

John Mbiti is another African philosopher who adds his perspective on the concept of a person in relation to the community in the African context. Many philosophers have

criticized his work this includes Kwame Gyekye, and some have referred to him as Tempel's follower because his work has its foundation from Tempel's version as well as the similarities between the two. Kaphagawani is one of the philosophers who criticized Mbiti's work. He referred to Mbiti as one of Tempel's chief disciples (2000: 72). This is because he thinks that Mbiti's work was not different from Tempel's work.

Unlike Tempel, Mbiti's account of personhood, focuses on the African setting instead of comparing Africans to the Westerners. In Mbiti's argument, he gives an account of what or how a certain clan or tribal group identifies themselves. This is not foreign to Africans because one of the ways in which one identifies themselves is through the tribal group, also known as the clan. Our identification as Africans includes the language, clothing, values and norms shared by a tribal group. In a similar vein, Matolino (2014: 50) states that "the first important feature is that each clan, as a people, has its own language, which is distinct from other people's language". He also adds the geographical location and ancestors (Matolino 2014: 50). Similar to the above scholars, Alvis Imafidon (2014) asserts that language differs from region to region. An example used by Imafidon is that PWA are called different names within South Africa alone even though it's the same country. For example, the Nguni clan, which is mostly from kwaZulu-Natal may refer to them as *isishawa*, while the Xhosa speaking people, mostly from the Eastern Cape, may refer to them as *ikhawu*, meaning monkey in English.

Temple also adds to his argument that in African communities', life is regulated by the kinship system. According to Mbiti the kinship system is a network that reaches to everyone and ensures that everyone is incorporated. This required that in a tribal group people must be related to one another and that no one who can be considered an outsider, should be included. Cited in Matolino (2014: 51) "everybody is related to everybody else, and there are many kinship terms to express the precise kind of relationship pertaining two individuals" Mbiti (1970: 136). With the above being said, it is important that one notes the never-ending cycle of relationships within people.

With regards to a person in the African community, Mbiti avows that it is the duty of a community to make or produce what they can consider a person because he believes that an individual depends on the community at large (Mbiti :1970 137). He, in addition, believes that the individual cannot exist without the community because individuals owe their life to others. This included the living, the deceased and those who are yet to be born. This is an indication that in African community there is an everlasting life, which is a circulation with no end.

For Tempel, the community has a role in the upbringing of a child, hence, in the African community, there is a belief in a maxim that states that “it takes the community to raise a child.” This means that no two parents can raise a child without the help of others. In fact, in African traditional societies, children are taught that every elderly woman is your mother, and every elderly male is your father, hence, they deserve as much respect as the parents at home. However, and most importantly, they have a duty to protect and guide the child as much as their biological parents do. When we speak of death, it is stressed that life does not end. This is because in African traditional societies, when a person passes on, it is believed that they are starting an eternal journey of being an ancestor. Mbiti’s (1970: 52) argument is based on the fact that the community comes first, and that the individual cannot exist alone.

### ***3.3.1.3 Ifeanyi Menkiti***

Ifeanyi Menkiti is another philosopher who added to the understanding of a person in an African community. He begins his argument by acknowledging the fact that there is a difference between the African and Western understanding of personhood. Like Mbiti, Menkiti argues for the importance of the community in the construction of self-identity. In his argument, Menkiti avows that “a human person is defined by the enviroing community” (Menkiti 1984: 71). This means that it is the community that you are in that makes you the person that you are. To a certain extent, his claim is true because when looking at issues affecting people with albinism, the issues are as a result of the conception of the community on albinism, hence, the community perceives them as not human. Furthermore, he adds that “the reality of the communal world takes precedence over the

reality of an individuals' histories" (Menkiti 1984: 71). By the above statement, Menkiti is confirming that in an African context, an individual is not more important than the community, affirming that Africans believe that the community has more value than the individual.

Like Mbiti, Menkiti asserts that Africans do not single out one characteristic or feature which is constitutive of personhood. For Menkiti, the community is the ontological determinant of personhood. To this, he states that "one obvious conclusion to be drawn from this dictum is that, as far as Africans are concerned, the reality of the communal world takes precedence over the reality of the individual life histories, whatever this may be" (Menkiti 1984 as cited in Matolino 2014: 55). The primacy is meant to apply not only to the ontological but also applies to epistemological accessibility.

In this argument, Menkiti also argues that attaining personhood is a long process meant to incorporate the individual to the community. This also ascertain that a person who does not undergo this process is not to be considered as someone who has attained personhood or a fully developed person. In this argument, he asserts that the community aids one in achieving personhood. He said "...and during this long process of attainment, the community plays a vital role as catalysts and as prescribers of norms" (Menkiti 1984: 172). An example of this is an initiation ceremony among the Nguni tribe called *Umemulo*. This ceremony is meant to introduce a young lady into womanhood. During this ceremony, elderly women in the community assist the young lady in learning what is expected of her at that stage of her life and ahead of her. The community's role is to confer that the lady is ready to move from one stage to the next and also celebrating with her family that she has complied with what was expected of her during the previous stage, and now she is ready to move to the next. It is evident that from ceremonies such as the above stated that the community are prescribes of norms as claimed by Menkiti. Matolino concurs and states that "the meaning of this claim is quite significant in Menkiti's theory. It seeks to show that the attainment of personhood is reliant on norms that are provided by the community" (Matolino 2014: 57). This then suggests that one is made a person by the community.

In addition, Menkiti believes that one can either fail or succeed in attaining personhood. People who succeed at attaining personhood or can be considered as a person in the African community are the ones who respect and follow social norms and rules, lives in solidarity with fellow humans and ensure that there is harmony with others. While people who fail to attain personhood are the ones who do not follow norms and do not live in accordance with the community's ethos. It is possible Menkiti's argument is based on the fact that a person who attains personhood is a person who promotes the well-being of the community and also who avoid self-centred actions and decisions.

From the foregoing argument, one can note that it is the duty of the community to confer on someone to have attained personhood. As a result, Menkiti believes that in cases of children, children are not important because they have not gone through the ontological processes that an adult would have gone through. As a result, he refers to children as 'it'. This is because in order for someone to be considered a person in the African community, Menkiti believes that there are stages the person needs to have undergone, and this also requires the approval of the community as indicated in some examples above.

### **3.3.2 Moderate communitarianism**

Moderate communitarianism is a view presented by Kwame Gyekye (1997). It is an objection of radical communitarianism but at the same time these two theories have similarities. Gyekye (1997: 41) ascertains that "moderate communitarianism aims to ascribe to both the community and the individual an equal moral standing". Unlike radical communitarianism, which only prioritizes the community, moderate communitarianism holds that rights and responsibilities have equal status. In a book called *Personhood in African Philosophy* (2014) Matolino asserts that the key defining characteristics of moderate communitarianism is that Gyekye "sees this radicalism as erroneous, hence he seeks to show that there are certain things that only belong to the domain of individual struggles and cannot be shared with the rest of the community" (2014: 63). The main idea behind moderate communitarianism is that the community does not override the rights of an individual. As such, the two should be considered equal.

Moderate communitarianism was born after Kwame Gyekye felt that Radical communitarianism has its shortcoming and thereafter gave his perspectives on communitarianism.

### ***3.3.2.1 Kwame Gyekye***

Kwame Gyekye is the father of a version of communitarianism called Moderate communitarianism. His version of communitarianism is an objection of radical communitarianism. He believed that the radical version of communitarianism has shortcomings and therefore saw the need for a new version of communitarianism. Gyekye attacked Mbiti and Menkiti's version of communitarianism because he felt that the above scholars have over emphasized the importance of the community. In his argument of moderate communitarianism, Gyekye also rejected Menkiti's position of claiming that "full personhood is attained when one is older and has been a member of the society for a long time". He claimed that the reason for the above is because it does not mean that older people are saints, hence, there are many elderly people who are considered ungenerous, insensitive or even wicked (Gyekye 1997: 49). For Gyekye, radical communitarianism is problematic because it does not recognise individual freedom. According to Matolino (2008: 77), "Gyekye claims that, although an individual is a social being, he is also other things". The "other things" that he made reference to are the abilities of an individual to make decisions and virtues.

His main argument here is to show that an individual cannot be said to be totally defined by social structures that they find themselves in because an individual is able to make important decisions, this includes setting goals for themselves. He agrees that even though some goals are set by the community, an individual still has a choice as to what their goals are despite what the community, they live in has set. In terms of individual freedom, Gyekye asserts that "it is necessary for one to make choices for the development of the self and the community at large". To this, he adds that:

in the light of the autonomous or near autonomous character of its activities, the communitarian self cannot be held as bound self, responding robotically to the ways and demands of the communal structure that structure is never to be conceived as reducing a person to intellectual or rational inactivity, servility and docility. Even though the communitarian self is not detached from its communal features and the individual is fully embedded or implicated in the life of her community, the self nevertheless, by virtue of or exploiting what I have referred to as its “mental feature” can from time to time take a distanced view of its communal values and practice and reassess or revise them (Gyekye 1997: 55-6)

From what has been noted above, Bernard Matolino noted shortcomings from both the radical and moderate communitarianism and introduced a different conceptualisation of the communitarian understanding of personhood. With regards to this study, one can note that there is a conflict between the radical and moderate communitarianism on the one hand and albinism on the other hand. This is because both the radical and moderate communitarianism promote the importance of the community. Radical communitarianism, on one hand focuses on the rights of the community more than individual rights. If one would use this theory, then the theory will allow the community to continue to do anything that they do towards people living with albinism. This is because this theory places the community above the individual. Moderate communitarianism on the other hand believes that the community’s rights and the rights of individuals are equal. By using this theory, there will be a conflict of interest because both those living with albinism and the community will be equal. It is therefore important that the study finds a theory that firstly, is recent communitarianism and secondly, consider the rights of people living with albinism.

### **3.3.3 Limited Communitarianism**

As an objection to radical and moderate communitarianism, Bernard Matolino introduced what he calls limited communitarianism. According to Matolino, his objection to radical



and moderate communitarianism is because these two theories fail to take the individual seriously. He asserts that “limited communitarianism differs quite significantly from moderate communitarianism in some important respects” (Matolino 2014: 161). He avows that the main difference between radical and moderate communitarianism is in the area of rights and the issue of primacy of the community over the individual (2014: 161). Limited communitarianism is of the notion that there are some rights that should not be taken away from people or that can never be broken. This limited communitarianism advocates for a different meaning or understanding of the community, which is putting the individual before the community. In addition, Matolino discusses the fact that “individuals are entities and that they are worthy of respect as a creation of God and her identity proceeds from God” (Matolino 2014: 183). This means that no matter how physically different a person might be, they should be respected for their humanity. This theory is useful to this research because it addresses both parties involved. It addresses people who violated the rights of others and addresses those whose rights are violated. So, by using this theory, I will challenge how the community is violating the basic rights of people living with albinism.

Bernard Matolino has recently proposed his version of communitarianism. His version came about as an objection to the radical and moderate communitarianism. He argues that this theory was introduced as a response to moderate communitarianism, which was also in response to radical communitarianism. Matolino proposed the theory of limited communitarianism because he regarded radical and moderate communitarianism to have failed to put emphasis on the rights of the individual. He considered moderate communitarianism, just like radical communitarianism, emphasised the primacy of the community and overlooked the issue of individual rights. As a starting point of his argument, he stated that there are some rights that cannot be violated. According to him “limited communitarianism states that there are certain individual rights that are inviolable” (Matolino 2014: 160). In this argument he introduces a new perspective on the notion of the community as opposed to other communitarian advocates.

Even though limited communitarianism is a version of communitarianism, Matolino places limitation on certain areas, that radical and moderate communitarianism failed to place. Limited communitarianism is based on the notion that a person is a social being. However, its limitations are based on the kind of claims that can be made about the metaphysical identity of persons from the fact that they are social beings. He identifies two main problems about the previous versions of communitarianism. The first being that personhood is attained when one fulfils duties that make the successful entities and the second being that the community's rights override that of the individual. As a result, he felt that radical and moderate communitarianism failed to take individuality seriously. Hence, he proposed limited communitarianism which takes the metaphysical orientation seriously. When it comes to issues of identity, limited communitarianism takes a different perspective as opposed to radical and moderate communitarianism. This is because radical and moderate communitarianism both hold that one can identify him or herself through the community. Whereas limited communitarianism objects the view that communal identity is real identity meaning that there are certain characteristics that make a person, not just the community. According to Matolino:

This means that limited communitarianism differs from all other communitarianism in that it does not recognise social identity as a matter of real identity. By real identity I refer to the actual element that makes up a person. These elements are not informed by perception or views of the community or a group of people. They are not even formed by the popular opinion or accepted moral codes of behaviour that are seen as ideal for individuals to uphold. These elements are not a matter of convention that is subject to judgement and third parties. (Matolino 2014: 170). Based on the above claim, Matolino proposes two types of identity. Limited communitarianism argues for two types of identity, namely the metaphysical view and social identity. He asserts that he proposed the above types of identity because the attributes from this view are believed to administer the person's whole existence and function (Matolino 2014: 166). According to Matolino, "without the key characteristics functioning the way they are supposed to, there is no person to really make reference to" (Matolino 2014: 166). Matolino argues for six reasons as to why the metaphysical view of persons should be taken with much seriousness.

When defending limited communitarianism, Matolino discusses what he thought was the appropriate relationship between the individual and the community. He claims that his main objective is to shift away from radical and moderate communitarianism, which argue that the community takes priority over the individual and argue that the metaphysical status of the individual is such a nature that nothing can go before that identity (Matolino 2014: 161). He therefore discusses six reasons in support of the view that the community should not come before the individual in the communitarian view of personhood. He avowed for the following reasons; firstly, he believed that the metaphysical view is true. To assert the above, he made reference to the Yoruba and Akan schemes. Matolino believed that the attributes from the above-mentioned schemes are true because they are “inherently identifiable with the identity of persons everywhere” (Matolino 20014: 16). This means that wherever you find yourself, every human being will have the attribute from this scheme.

Matolino’s second reason is that “it is free of serious confusion and alarming contradictions that surround both radical and moderate communitarianism” (Matolino 2014: 162). He disregards radical and moderate communitarianism because he thinks they are built on a mistake. His third reason is that he saw the metaphysical view as being simple. His fourth reason is was that he considered the metaphysical view as independent. He believes that this view does not depend on any other position. The last reason that he named was the fact that the metaphysical view is purely philosophical.

Limited communitarianism is of the view that in issues of personhood, priority has to be placed on the metaphysical view. This type of communitarianism is of the view that the metaphysical view is informative because it emphasises what a person is, and it is strictly a matter of identity. It must be noted that Matolino’s argument here is not very different from the other forms of communitarianism but what makes his argument different from others is the fact that he does not over exaggerate the importance of the community. On the contrary, what he does is to seek or develop a version of personal identity that is not community oriented.

The second type of identity that he mentioned was the social or communal. For this type of identity, a person's identity is created by the community. Matolino asserts that for limited communitarianism, social identity is born when one perceives themselves as being part of the community or a particular group of people (Matolino 2014: 167). This is where limited communitarianism is different from other forms of communitarianism. It does not perceive social identity as real identity. Social identity includes the following elements: firstly, on how one is seen by the community. This means that the person's identity also depends on the community's perception of who they are: secondly, on how one is supposed to be. This means that there are certain characteristics and attributes that one should have in order to be classified as a person in the community: fourthly, on what the community expects one to be. This fourth reason is similar to the second. This is what the community wants you to be, for example, if you are born in a certain family with similar attributes, one is automatically expected to have the same attributes. Thus, it must be also acknowledged that the community plays a role in the formation of social identity.

Limited communitarianism notes the importance of the community as "makers of social identity" but it asserts that it should not be given complete importance in matters of sociality issues because it is not absolute matters of one's proof of identity (Matolino 2014:172). What Matolino means here is that as much as the community makes certain identity, this does not mean that a person should be identified by this. For example, people who drive small cars can be perceived as being middle class people, whereas the person might have reasons as to why they prefer smaller cars. The same goes for a person who drives a big car, this does not mean that the person is rich, because it might be that the person lives a life that he or she cannot afford. A second example is that, when people see someone in the library, they automatically assume that that person is going to study, whereas it is likely that that person prefers to play games on their phone in a silent environment. There are certain situations which lead people to assume certain things about others. Matolino there asserts that this kind of identity should only be applicable to those who believe in it but should be taken as an element that makes one a person.

Matolino proposed a new version of the relationship between the communal and metaphysical identity. He claims this relationship will be the foundation of limited

communitarianism. According to him “firstly, limited communitarianism argues that the metaphysical aspect of identity can come into being without the aid of the community” (Matolino 2014: 174). Here, Matolino attempts to illustrate that before anything, persons are God’s creations. Thus, the community does not have influence of impact in the process of human formation. This is the assertion that before being part of a community, a person is an individual created by God. Secondly, “the community cannot exist without voluntary association of individual person” (Matolino 2014: 174). This shows that a person chooses to associate him or herself with a group of people. Individuals have the right to decide if they want to be identified with a certain group or not, for example, if one wants to join a certain political group or not. Thirdly, according to Matolino “the reality of the individual really matters to that individual” (Matolino 2014: 174). How you are, what you do, how people treat you, are some of the most important areas in one’s life. How people identify you as something positive or negative will have an impact in your life. For example, during the apartheid, being “black” people were considered as slaves did not see themselves as being anything else but a subordinate to a white person. As a result, being a slave, for example, was something ordinary for them because it was their reality.

### **3.4 Arguments against limited communitarianism**

Oyowe is one of the scholars who has critiqued limited communitarianism. In his article called “This thing called communitarianism: A critical review of Matolino’s Personhood in African philosophy,” (2015) Oyowe believes that Matolino’s book raises three provoking issues. He thinks that Matolino’s account of communitarianism is a repetition of what has been said by the other versions of communitarianism. He avows that Matolino is not showing commitment about what it is that his version of communitarianism is about, that is, how different it is from radical and moderate communitarianism. As a confirmation of the above, Oyowe asserts that “limited Communitarianism’s admission of this constituent of personhood inherits this commitment and implicates it in the communitarianism game even at the level of metaphysics” (Oyowe 2015: 514). Oyowe also finds limited Communitarianism problematic based on the fact that he thinks it is “specifically looking at the Yoruba and Akan and other culture specific accounts of

personhood.” This means that Matolino should have been biased when considering his account of personhood. Oyowe believed that for limited communitarianism to be a concept, Matolino should have proposed elements of personhood that do not account for communal features for it to be different from what been said by the other versions of communitarianism. On the contrary, Oyowe acknowledged that there is one difference between the foregoing type of communitarianism and radical and moderate communitarianism. This difference lies in the area of rights, that is, whereas the radical and moderate communitarianism give the community precedence over the individual, Matolino’s Limited communitarianism gives the individual precedence of the community.

The second scholar to critique limited communitarianism is Mesembe Ita Edet (2015). His critique was similar to Oyowe’s critique. He similarly states that limited communitarianism, as proposed by Matolino, is not different to the previous types of communitarianism. Furthermore, Edet asserts that Matolino made an error when he claimed that Moderate communitarianism did not take individuality and human rights seriously. He avows that for limited communitarianism to be a new concept, Matolino should not have made the same mistakes as radical and moderate communitarianism. According to Edet, the shortcoming of limited communitarianism is that it “did not address Ubuntu concept of personhood” (Edet 2015: 103). In addition to the above, Edet claims that, Matolino “did not take seriously the epistemic dimension of the subject of personhood” (Edet 2015: 103). Edet therefore proposed a new concept of personhood because he thought that Matolino failed in clearly separating the relationship between communitarianism and the metaphysics of personhood with what has been said by Oyowe and Edet about limited communitarianism. This study will still be using limited communitarianism as a theory that will analyse the issue at hand. This is because this theory speaks to two major areas that is of importance to this study, namely, the individual rights and social identity.

Limited communitarianism will guide this study because it is a communitarian ethical theory that advocates more on the rights of the individual and the punishment of the perpetrators, which is something important to this study. However, the researcher has noted that there are shortcomings in this theory, especially when seeking to find elements one

should consist of when seeking to confirm one's personhood. Matolino's metaphysical view paid attention to the physical characteristics of a person, specifically focusing on the Yoruba and Akan schemes. The researcher then proposes that, there is a need to include the ancestral lineage when considering what makes a person. The researcher suggests this because when seeking to find out if someone is truly a person, their ancestral lineage should be one of the most important of elements that confirm their personhood. This is because if we can trace their ancestors then with no doubt, we can confirm their personhood. In Africa, an ancestor is someone who is deceased but believed to be living eternally, because of the life they lived and good relations they had with others when they were alive. When making reference to the belief that people with albinism are not human for example, the researcher has analyzed the metaphysical elements but in addition the researcher would like to add the ancestral lineage of people with albinism. This is closely related to the *Ntoro* and the *Mogya* by Wiredu (1980:47), which are the characteristics passed down to a child from both the parents. The researcher is using this to provide evidence that if people living with albinism are born from human parents, this means that they should be considered to be human.

People living with albinism cannot be considered not human for the following reasons; they have *Ntoro* and *Mogya*, and characteristics, which they inherited from their parents. The main focus of this section is the ancestral lineage, which is important in an African community. Since the above proves that people with albinism have the foregoing characteristic, this qualifies them to have ancestral lineage. For example, if PWA were to draw up a family tree, evidence will show that they have grandparents, furthermore, forefathers. For me, it is the first reason why considering ancestral lineage is important.

In addition to the above, the second reason to consider ancestral lineage, which is not part of the ethical communitarian ethics discussed in chapter three, is the importance of one becoming an ancestor in the African traditional community. Becoming an ancestor is very important for the African people. If people living with albinism are not considered human, the result will be that they will be thought of as not having eternal life, meaning that no one will consider them as ancestors. Ancestors are important because it is believed that they

serve as intercessors between the living and God. African people, at least in my culture, which is the Nguni tribe, are known to be our representatives to God.

A *Nguni* ceremony that shows the importance of ancestorhood is called *ukubuyiswa*. Munyaradzi Felix Murove (2016) used the example of the *ukubuyiswa* ceremony to show the importance of ancestors in the African community. He notes that:

This ceremony is an important one: which has been observed by our ancestors from time immemorial. This ceremony, and the rituals that accompany it, demonstrate that the deceased has been reunited with the members of the family who are still living, and with the departed ones. S/he is no longer a wondering spirit but is also integrated into the ranks of the ancestors. From now onwards the family can appeal to the deceased for blessings and protection. On the other hand, the family is required from time to time to slaughter and brew beer in recognition of the presence of the deceased among them.

Considering the above, Murove has highlighted the importance of ancestorhood, which I think is an important characteristic one should look into when considering personhood. However, people living with albinism are deprived the opportunity of becoming ancestors by fellow humans. This is because some of their bodies are not found, occasionally burnt or buried. As a result, ceremonies such as *ukubuyiswa* cannot be performed for them. The major reason for the above stated is due to beliefs, which results in myths such as, “they do not die but they disappear”. People living with albinism do not disappear, but their bodies are not found because they are killed brutally, and their bodies are discarded without the family having the opportunity to bury them.

Limited communitarianism is the key theory that will guide this study because the matter of the metaphysics and individual rights is very important when looking at a phenomenon like albinism. The metaphysical view will serve as a description of what attributes should something have in order to be referred to as a person. Thus, if it can be proven that people with albinism can be considered persons because of the metaphysical attributes they hold,



this can lead us to the second element of this theory that is as important as the first one. The issue of rights, for this matter societal rights and individual rights. For the sake of this research, the researcher will pay more attention on the rights of the individuals. This is because the previous types of communitarianism have placed their focus more on the community rights as opposed to as individual rights. The study intends to analyse the belief surrounding albinism from an African context using the communitarian theory. This theory will help me to prove that in an African community, people living with albinism still have rights and that there are some rights that cannot be violated. This theory will help the researcher to challenge the beliefs on albinism. It will also help me to prescribe what ought to be done to deal with the people who violate the rights of people living with albinism.

### **3.5 The Rights-Based Theory**

Limited communitarianism is the key theory that will guide this study because the matter of the metaphysics and individual rights is very important when looking at a phenomenon like albinism. The metaphysical view will serve as a description of what attributes should something have in order to be referred to as a person. Thus, if it can be proven that people with albinism can be considered persons because of the metaphysical attributes they hold, this can lead us to the second element of this theory that is as important as the first one. The issue of rights, for this matter, societal rights and individual rights. For the sake of this research, the researcher will pay more attention on the rights of the individuals. This is because the previous types of communitarianism have placed their focus more on the community rights as opposed to individual rights. The study intends to analyse the belief surrounding albinism from an African context using the communitarian theory. This theory will help me to prove that in an African community, people living with albinism still have rights and that there are some rights that cannot be violated. This theory will help me to challenge the beliefs on albinism. It will also help me to prescribe what ought to be done to deal with the people who violate the rights of people living with albinism.

### **3.6 The Critiques of the Rights-Based Approach.**

#### **3.6.1 Arguments against the Rights Based Approach**

Empirical critiques of human rights have gradually increased. Empirical evidence is often called upon to reveal the ineffectiveness of human rights standard, advocacy and policy. Concerns of sociological legitimacy, material effectiveness and distributive equality are foregrounded and undergirded by the growing body of empirical evidence (Langford 2018: 24). According to Hopgood (2014: 1), “international regime and secular religion of human rights is crumbling because of its “systematic ineffectiveness” and “lack of democratic accountability”. This critique sees an absence of sociological legitimacy, the community is ought to validate human rights, this is done through what is called social contract. This is because what maybe right to one person may be considered wrong by another. Therefore, there is a conflicting interest for example, the right to life and the right to religion. It is generally agreed that all persons have a right to life and a right to religion. What one may ask is what happens when both these rights are in conflict. It is possible, for example, for a certain culture to believe in the killing of others in order to survive, whereas all human beings have a right to life.

#### **3.6.2 Arguments for the right based approach**

This theory is most closely associated with human rights. John Locke who developed this theory is said to have imagined the existence of human beings in a state of nature. “In this state, men and women were in a state of freedom, able to determine their actions, and also in a state of equality in the sense that no one was subjected to the will or authority of another” (Shestack 1998: 207). This means that this theory is advocating for liberty and equity similarly like the right-based approach. Human rights and the respect of human rights is very important. This ensures order in the society, making sure that even the most vulnerable is protected. Human rights ensure that people have a sense of belonging and equality. Looking at the issue of women and patriarchy before the era of feminism and women’s rights. Women were oppressed and were not as free as they should be. And since their rights were advocated for, they are liberated and slowly becoming equal to men.

The right based theory will be used to describe the rights of PWA that are infringed or violated. The right-based approach describes which of the rights that are violated as a result of the African traditional beliefs towards people living with albinism. This violation of rights is as a result of African traditional beliefs that not regard PWA as being persons or beings that are, or, should be part of the community. As Matolino advocates, traditional communitarianism underestimated the importance of individual rights although, in contemporary Africa, the issue of rights is of most importance. This approach on the other hand, emphasizes on the inclusion and importance of individual rights.

### **3.7 Conclusion**

This chapter is the theoretical framework of the study. it explains and discussed communitarianism. The type of communitarianism used for this dissertation is called limited communitarianism. Limited communitarianism is different from radical and moderate communitarianism because it places emphasis on two important factors such as the metaphysical view of a person and acknowledges that individuals have rights that cannot be violated.

With regards to my research, one notes that there is a conflict between the view of radical and moderate communitarianism and the aim of this study regarding albinism. This is because both theories promote the importance of the community. Radical communitarianism focuses on the rights of the community more than individual rights. If one should use this theory, the theory will allow the community to continue to do anything that they do towards people living with albinism. This is because this theory places the community above the individual.

Moderate communitarianism on the other hand holds that the community rights and the rights of individuals are equal. By using this theory there will be a conflict of interest because both those living with albinism and the community will be equal. Using this theory will result in the community having rights to discriminate and inflict pain in people living

with albinism. It is therefore important that to find a theory that firstly, is recent and secondly, consider the rights of people living with albinism and will advocate for the punishment of those who infringe on the rights of others. Hence limited communitarianism is the most suitable communitarianism to guide this study. To justify or elaborate more on the choice for limited communitarianism, when it comes to issues of rights, the study refers to the right-based theory in order to explore some of the rights that are violated. The study limits itself to basic human rights, rights that are aligned with Matolino's views.

The next chapter is chapter four, which is the analysis. Using the foregoing theories, I will analyse the African traditional beliefs surrounding albinism.

## Chapter Four – The analysis and Findings

*“All human beings are born free and equal in dignity and rights. They are endowed with reason and conscience and should act towards one another in a spirit of togetherness. No distinction shall be made based on the political, jurisdictional or international status of a country or territory, to which a person belongs, whether it be independent, trust, non-self-governing, or under any limitations of authority”.* (The Declaration of human rights 1948)

The above quotation is of value to this study. It serves as guidance as to what an individual is entitled to and how people should treat each other. This quotation incorporates two elements that is of value to this study. These are respecting the idea that all human beings are born free and equal in dignity and rights but also encourages’ people to live harmoniously with one another. With the issues of rights that are discussed in this chapter, it is important to have the above quotation in our thoughts.

### 4.0 Introduction

The previous chapter dealt with the theoretical framework of the study. The theories that have guided this study so far are limited communitarianism and the rights-based approach. As noted in chapter three, limited communitarianism is a communitarian theory that holds that there are certain human rights that are inalienable, and as a result, individual rights ought to take precedence over the community. In a similar vein, the rights-based approach advocates for the primacy of human rights and for individuals to live harmoniously. As a result, these two theories have guided this study to critically assess the African traditional beliefs surrounding albinism. The current chapter looks at the African traditional beliefs surrounding albinism through the lens of limited communitarianism and the rights-based approach. In this chapter, the study discusses the findings of the research. The first point to analyse or explore when one wishes to gain an in-depth understanding of people living with albinism is to consider whether people living with albinism are persons. The study limits itself to the Yoruba and Akan schemes that have been discussed in chapter two and of which Matolino refers to in discussing the metaphysical characteristics that one should

have in order to be considered a person. The metaphysical identity focuses on the key elements that make up a person. In this study focus is placed on the common characteristics provided by the scholars discussed in the literature review of this study, this includes the following; the body, the mind, individual spirit. From the above African conceptual schemes of a person, people with albinism should be considered persons.

Another area which is important in the metaphysical identity of a person is the one found in the *Ntoro* and *Mogya*, which is similar to the biological perspective that claims that albinism is an inherited disorder that needs a combination of certain types of genes from both the mother and the father. This alone should be evident that PWA are persons because for one to be human they need to be born from human parents. Human parents cannot give birth to a ghost or monkey, as suggested by some of the beliefs. Albinism is the pigmentation of the eye, skin and hair, genetically inherited and non-contagious (Ester Hongs, 2006: 06; Nontobeko Bila et al. 2015: 01; Stine Braanthen & Benedict Ingstad 2006: 600). In a similar vein, Caradee Wright (2015: 27) asserts that albinism is a genetically inherited disorder that is caused by a lack of melanin and can be harmful to a person.

#### **4.1 People Living With Albinism are Human**

Through the lens of limited communitarianism, the first issue that came up is that people living with albinism are human, unlike the popular assertions. People living with albinism are called by different names, some of which do not refer to a human being. Explaining the reason for such behaviour or treatment, Imafidon (2017) describes the categories of being in African tradition. However, in connection to albinism, emphasis will be on what he calls “queer beings”. He describes “queer” as something that is at variance with what is usual or normal if it differs in some odd or strange way with what is ordinary (Imafidon 2017: 38). “Queer of beings” in African ontology is a being who is visibly human but may lack some qualities. Hence, queer beings may look human, but they are not regarded as humans or treated as humans in African traditional society (Imafidon 2017: 18). All persons with albinism have characteristics of being human except for the pigmentation, hence, they are

excluded from the category of being. In most African societies people living with albinism are perceived as different and unusual, which has led to their stigmatization as seen in chapter two.

- a) Dapi (2018: 12) and Cruz-Ingo (2011: 81) assert that in Africa people living with albinism are considered as ghosts.
- b) In addition, some people associate people with albinism with negativity, for example, in South Africa, among the Nguni tribe, PWA are called *Isishawa* which means curse (Imafindon 2017: 47).
- c) Some tribal groups or countries refer to PWA as animals while some associate them with negativity, for example, among the Xhosa speaking people in South Africa, they are referred to as *Inkawu*, which means monkey in English.

#### **4.1.1. People Living with Albinism are Social Beings**

Another issue that comes to the fore when looking at albinism and the beliefs surrounding people living with albinism, through the lens of the theories discussed in chapter three is that they are social beings. Since people living with albinism are socially excluded or seen as the other, the community constructs ideas about their identity, which results to be their reality. Typically, the words beliefs, myths and superstitions are used interchangeably but this should not be the case. For the purpose of this study, they would not be used interchangeably because they have different meanings for this study. The beliefs are what people see albinism to be, which has led to misconceptions and realities of people living with albinism. The myths and superstitions surrounding albinism are constructed by the community. The social construct theory is a theory that asserts that our realities are agreed upon and created by the community. In chapter two, the social construct theory was discussed in detail.

One of the contemporary myths around albinism is that having sexual intercourse with a person living with albinism will cure a person who is infected with HIV/AIDS. In South Africa, especially in the rural areas, many believe in this myth. As a result, there has been an increase in the rape of number of a women living with albinism. This makes these women unsafe and live in danger. This is also a reason why there is an increase in the

amount of deaths of people living with albinism. Some of the superstitions include the following: a woman had sexual intercourse with a *tokoloshe*, a white person or that she is cursed for her wrong doings. Another famous myth is that if one has any form of relationship with a person with albinism, they will give birth to a child living with albinism.

One's identity depends on how the community perceives who they are. It is also important that it is noted that if it can be proven that one is a human being, therefore, one is a social being. Today, as noted in chapter two, the problem of stigmatization of people living with albinism still continues. This is problematic because in some countries, people need to leave their homes and find safer places to live. These actions contradict the African way of life and the African communitarian way of living. The Ubuntu principle that Africans value so much is lost when looking at this phenomenon. Therefore, Barker et al. (2010: 173), argues that "life in Southern Africa still centers on the community in which one lives and consequently the attitude of those people towards albinism is fundamental to their life experience". This is an assertion that a change in the mind-set of the community would make a difference in the living conditions of the people living with Albinism.

As mentioned above, people living with albinism have to live in isolation because they suffer from social exclusion. Barker et al. (2010: 174), argues that, "this still continues, and still present today because children living with albinism are prevented from mixing with others because of the fear that their "diseases" will spread". This alone has a negative impact on children living with albinism from a young age. This child would have very few friends, if any at all. Some parents stop their children with albinism from starting or finishing school because of fear. The parents see the need to always keep them under their care to avoid any attack or avoid their children being killed because of their condition.

Most people living in South African communities disapprove of people living with albinism because of their condition which brings about a difference in appearance, instead of them being valued for their humanness. This is due to the mindset that people have about them, the mindset of thinking that people living with albinism are different people. As a result, they have to live with name-calling and stigmatization. The most common name



they are called is “umlungu,” which is directly translated as ‘white person’, thus we see the injustices and stereotype they face. This is an indication that the community sees them as people who are totally the opposite from them. As noted in chapter two, Cruz-Ingo et al. (2011: 84), argues that “many people living with albinism have been referred to hide out in secluded rural areas, often separated from their families and friends”. This is because people living with albinism in South African communities live in fear of being violently attacked and killed. There are many reasons why people think another may inherit albinism. These reasons differ; from it being the mother’s fault to because the family is cursed. Others think that a person who lives with albinism is brought to the family by ancestors to bring financial freedom. As a result, Barker et al. (2010: 172) argues that because of the different associations made with albinism and the stigmas that people with albinism have to suffer from, many children with albinism have to be raised by single mothers, because fathers often leave at birth when they see that the child has this condition.

According to limited communitarianism, there are two types of identities, one of which is the social identity. This type of identity can be referred to as the social or communal identity. According to social identity, a person’s identity is created by the community. He asserts that for limited communitarianism, social identity is born when one perceives themselves as being part of the community or a group of people (2014: 167). This is where limited communitarianism is different from other forms of communitarianism. It does not perceive social identity as real identity. Social identity includes the following elements: 1. How one is seen by the community, which means that the person’s identity also depends on the community’s perception of who they are. 2. How is one supposed to be, which means there are certain characteristics and attributes that one should have in order to be classified as a person in the community. 3. What the community expects you to be. This third point is similar to the second. This is what the community wants you to be, for example, one born into a certain family with similar attributes, is automatically expected to have the same attributes. Thus, it must be also acknowledged that the community plays a role in the formation of social identity.

This type of identity is what the community expects from those they can classify as a fellow human being. This involves how a person sees themselves as part of the community. People with albinism cannot identify themselves as being part of the community mainly because they are not seen by the community as part of their own. What follows below is a discussion of social identity as explained in limited communitarianism.

Limited communitarianism discusses three elements of social identity, the first element being; “How one is seen by the community” (Matolino 2014: 167) meaning that the person’s identity also depends on the community’s perception of who they are. People living with albinism are considered as the ontological other in the African community. The beliefs surrounding albinism show that they are not seen as human beings because of the physical difference. How one is perceived by the community can have a positive and a negative impact on one’s life. For example, if one drives a big car, people will automatically assume that the person has money and such a person is respected. However, if one drives a small car, the person is considered a middle-class person and ends up somewhat overlooked even though the person may be a rich person who simply prefers to drive in small cars. The point here is that how one is perceived is their judgement of who you are but not your identity. Moreover, it is important to note that this is not who you are but only how the community identifies you.

The second element is; “How you are supposed to be” (Matolino 2014: 168), this means there are certain characteristics and attributes that one should have in order to be classified as a person in the community. In the case of PWA, they are not classified as humans because they are not pigmented as people without albinism. They are not considered as humans because they are pigmented differently from what is known to be normal. This is also present in modern communities, for example, people have their idea of how an ideal woman should look like. She is expected to be slim, have long hair and light skinned, as a result, people who do not have these characteristics see the need to look like this in order to fit in. Similarly, the community thinks that a person should have a certain type of pigmentation and in order to be considered a human being, and if they don’t, that means they are not human.

The third element is, “what the community expects you to be” (Matolino 2014: 169). This reason is similar to the second one above, and it is what the community wants you to be. Africans have their own perception of what a person should look like. For example, for one to attain personhood or to be considered as a person, one should have brown/black eyebrow, hair and skin. People living with albinism do not meet the expectation of what the community wants its members to look like or have the traits they are expected to have. However, from the above discussions it is clear that people living with albinism are social beings who can participate meaningfully in the community.

#### **4.2 People Living with Albinism have rights**

The fact that PWAs are human and social beings, it stands to reason that they have rights. The general assembly of the UN declared the universal declaration of human rights in 1948. This declaration was set as a common standard of achievement for all persons and nations. People possess human rights from birth, regardless of their colour, ethnicity, sex, religion, culture, or educational background. According to the 1948 UN human rights declaration, “all human beings are born free and equal in dignity and rights. They are endowed with reason and conscience and should act towards one another in a spirit of togetherness. No distinction shall be made on the basis of the political, jurisdictional or international status of a country or territory to which a person belongs, whether it be independent, trust, non-self-governing, or under any limitations of sovereign” (UN universal declaration: 1948). This has been discussed in-depth in chapter two.

##### **4.2.1 PWA have the right to Freedom and security**

Article 2 of the Declaration reads: “Everyone is entitled to all the rights and freedoms set forth in this declaration, without distinction of any kind, such as race, color, sex, language, religion, political or other opinion, national or social origin, property, birth or other status”. (The UN universal declaration of human rights on the 10th of December 1948). In this article, one notes that the status or social origin of people living with albinism should not be used against them. This article puts emphasis on the fact that every human being should enjoy their human rights regardless of their condition. People living with albinism are discriminated against mainly because of the color of their skin, this is a violation of one of the most basic human right.

Section 12 of the South African Bill of Rights is about freedom and security. The study specifically looks at subsection C to E of this section. 12. (1) “Everyone has the right to freedom and security of the person, which includes the right— (c) To be free from all forms of violence from either public or private sources; (d) Not to be tortured in any way; and (e) Not to be treated or punished in a cruel, inhuman or degrading way.” (The Constitution of the Republic of South Africa, 1996).

From the above quoted section and looking at what people with albinism have to go through, one notes that the rights of persons with albinism are infringed upon. They are not free from violence because just like Cruz-Ingo et al. (2011: 79) noted, they are hunted for their body parts. In some cases, they are hunted by relatives or family members due to the belief that they will acquire wealth if they used the body parts of PWA to prepare *umuthi*.

#### ***4.2.1.1 People living with albinism should not live in fear***

People living with albinism and their families live in fear. This is because they know that they are targets of people who want to better their lives. They are faced with the challenge of not being able to flourish and get the opportunity to better themselves. As a result, some of them feel the need to relocate to safer locations because of the fear of being attacked and killed. In Tanzania, it is said that people living with albinism live in fear so much that they have to leave their homes and stay in a shelter with soldiers looking after them. In South Africa, especially in the rural areas people are afraid to let their kids go to school because they fear that they will not come back home. In a famous South African film called *Uzalo*, this is a series in South Africa, that shows from 20:00 to 20:30 every weekday, it featured albinism awareness, where they showed a young girl who was living with her grandparents. The story shows that her family was living in fear, and everyday her grandmother prayed that she would come back home safe. It went to the extent that a family friend had to walk her to school and fetch her because they feared for her life.

#### **4.2.2 PWA have the right to life and liberty**

Article 3 of the declaration reads: “Everyone has the right to life, liberty and security of person.” Article 3 therefore questions all that is happening in the communities around South Africa. People living with albinism have a right to live but, people living with

albinism are being killed for the use of organs, while others flourish with those organs. The right to liberty and security, people living with albinism in South African are deprived of their freedom, as mentioned in chapter two, some need to be relocated to ensure that they are safe, while others cannot do daily activities, like attending school, like any child would. People living with albinism live under fear of their lives because they are afraid for their safety.

Killing and torture is inflicting pain on another. Usually, people who are tortured suffer from mental issues such as trauma, this will be discussed further below. Some stories in the reports from Under The Aame Sun show that some people living with albinism are tortured before being killed. This is because, it is believed that body parts should be removed while the person is still alive in order to make *muthi*. Some are sexually violated before they are killed.

Section 12 of the South African Bill of Rights is about freedom and security. This study will specifically look at subsection C to E of this section. 12. (1) of the Bill of Rights “Everyone has the right to freedom and security of the person, which includes the right—

- (c) To be free from all forms of violence from either public or private sources;
- (d) Not to be tortured in any way; and
- (e) Not to be treated or punished in a cruel, inhuman or degrading way.

(The Constitution of the Republic of South Africa, 1996).

This section of the Bill of rights looks at the right to freedom and security. People living with albinism in South Africa are tortured and killed for their body parts because they are seen as a means of giving the other people an opportunity to thrive.

People living with albinism are found in all races and nations globally. However, there is still a lack of knowledge about the albinism disorder, especially in South Africa. As a result, people living with albinism cannot feel secure in their communities because of the negative perceptions that people have about Albinism. Salewi (2011: 8) argues that “people with albinism have grown to be vulnerable to attacks and unwarranted killings from person who believe that their body parts and limbs of people with Albinism can be superstitiously used

to generate income”. In South Africa, people living with albinism suffer emotionally and physically because they live in fear of being hunted down for their body parts (Cruz-Ingo et al. 2011: 79). All the above-mentioned issues are due to the myths and superstitions that people have that the body parts of people living with albinism bring about wealth and health.

It can also be argued that some of these killings are a result of the black-market. This is due to the fact that human organs are in demand and formal procedures are expensive and also because one may have to wait for a long time for an organ. People living with albinism may be easily target especially because they are seen as not human, and because their killings are a common thing people will not know the reason even if it is associated with the trading of human organs on the black market.

People living with albinism are tortured physically and mentally. This is because they do not know when the next attack will be. A number of them live in fear of doing basic daily activities such as taking children to parks while others are deprived from acquiring education. They are punished and treated in a cruel way just because they appear to be different, just because people use them (their body parts) as a means of reaching a particular end (wealth and protection from bad luck) rather than seeing them as an end in themselves. Immanuel Kant argued against the use of human beings as a means to an end. He says that it is important that people act for the sake of the moral law. He also asserts that human beings are rational beings worthy of dignity and respect. He bases his theory on the fact that as humans we have duties and obligations. Discussing Immanuel Kants means to an end Lara Denis (2007:246) asserts that

An end is that in virtue of which an agent determines herself to action, an object out of concern for which she acts (Kant, ‘Groundwork’ 78 [4:427–8]). An end in itself is an objective end, meaning that its status as an end is grounded in reason, independent of inclination, and thus is an end for all rational beings. It is an existent end, meaning that it is not a goal to be affected, but rather an already existing thing that is to be respected, honored, supported, and enhanced. Finally, it has absolute worth, meaning that its value does not depend on inclination. Most commentators see Kant as using

‘absolute worth’ and ‘dignity’ to refer to the same sort of unconditional value, and thus take absolute worth to imply that the end in itself has a value incommensurably higher than the value of anything else (84 [4:434–35]).

One may ask the question, thereafter, of whether, the killings of people living with albinism in South African are the right action? Or is it the killing morally correct since the perpetrators want to be rich? Can the above be universalized?

Another issues that is a result of the beliefs surrounding albinism is abduction. Abduction is the forcefully taking of someone from their place of comfort and holding them against their will. The number of people living with albinism who are abducted has increased over the past years, this has been proved by the reports in the appendices.

The study makes use of a recent example that occurred at Mpumalanga in South Africa in early 2018. In January of 2018, the kidnapping of two children made headlines across South Africa. 13-year-old Gabisile Shabane, who was living with albinism and her 15-month old nephew Nkosinathi Ngwenya, were kidnapped from their homes at Hlalanikahle in eMalahleni, Mpumalanga, South Africa. They were kidnapped by three men who entered their home after breaking a widow.

Reports showed that Nkosinathi Ngwenya’s body was found on the side of the highway while Gabisile’s body was found buried with some of her body parts missing. It was said that one of the accused men, the one who initiated the killings, wanted the girl’s body parts because he needed to be cleansed and wanted to remove all of his bad luck. It was said that one of the accused, Msibi, and a traditional healer, who was also part of the group of people who planned the killing, took Gabisile’s private parts so that the business that Mbisi had would thrive.

Based on the beliefs, myths and superstitions that there is something extraordinary about people living with albinism and that there are spiritual powers associated with their body there has been an increase in the amount of cases against PWA. Gabisile was one of many South Africans who were killed because of the belief that their body parts are good ingredient for rituals. There are two contradicting sides to these myths; firstly, there is the belief that the body parts of persons living with albinism will bring wealth and health;

secondly, there is the belief that people living with albinism bring bad luck. These are some of the reasons why they suffer from social exclusion.

#### **4.2.3 PWAs have a right to Human Dignity**

As already noted, Article 1 of the Declaration reads: “All human beings are born free and equal in dignity and rights” (The UN universal declaration of human rights on the 10th of December 1948). According to declaration of Human Rights, people with albinism and people living without albinism have equal rights and deserve equal dignity. This therefore implies that they deserve respect and protection from any form of harm like any other individual. Looking at the killings of persons with albinism and making reference to the declaration of Human Rights, this study asserts that the killings, stigmatization, and violent attacks are infringing upon this human right.

The Bill of Rights is the part of the Constitution that has had the extreme impact on life in this country. As the first words of this chapter says: “This Bill of Rights is a cornerstone of democracy in South Africa. It enshrines the rights of all people in our country and affirms the democratic values of human dignity, equality and freedom” (The Constitution of the Republic of South Africa, 1996).

Section 10 of the bill of rights is about human dignity. It states: “Everyone has inherent dignity and the right to have their dignity respected and protected” (The Constitution of South Africa, 1996). The killings and attacks are against this section 10 of the South African Constitution. People living with albinism are not treated with dignity, in fact, they are treated inhumanely. This section serves as guidance of how all human beings should be treated. Firstly, for the fact that one is human, they should be protected and treated with respect. Secondly, it is important that people living with albinism should be protected more than others because they have special needs and they have become a vulnerable group of people in the African community. Giving birth to a child that is different makes it important to take extra precautions with them because some people who are born different have issues accepting their differences which leads them to excluding themselves. This is similar to the social construct theory which is discussed in chapter two, this theory asserts that the community’s perception about yourself becomes your reality.



Another common belief surrounding people living with albinism is that; having sexual intercourse with a person living with albinism can cure a person who is infected with HIV and AIDS. HIV and AIDS is a common virus in South Africa, and some may think it is overrated because people hear about this virus almost every day. Nevertheless, some still have stigmas about this virus and do not want to talk about it at all even though there has been so much education about this virus. HIV and AIDS Information Booklet (2005: 2) defines HIV and AIDS as

HIV as (Human Immuno Deficiency Virus) is a virus that enters the blood. In HIV positive people, the virus can be found in the blood, sex fluids (such as sperm and vaginal fluids) and breast milk. In addition, HIV causes AIDS (Acquired Immuno Deficiency Syndrome). HIV slowly damages the immune system (the army) if it gets into a person's body. This means that the body starts to lose its ability to defend itself against germs, infections and bacteria such as TB.

This disease cannot be cured but it can be managed through taking care of one's body, eating healthy, and exercising, and most importantly, taking medication and using condoms for sexual intercourse. The government of South Africa is supplying free chronic medication for the people who are infected with the infection and free condoms to ensure that people are able to protect themselves.

In chapter two, scholars like Bradbury-Jone (2018), Bila et al (2015), Barker et al (2010) and Machoko (2013), highlighted that it is believed that having sexual intercourse with a person living with albinism is a cure for HIV and AIDS. This has caused people living with albinism to become victims of rape. Bradbury-Jones (2018: 8) did a study to find out people's perceptions on albinism. This study had an equal number of people who are living with albinism and people without albinism. Some of the people in this study shared that they were taught to believe that when someone who is HIV and AIDS positive has sexual intercourse with a person living with albinism they will be cured from the disease (Bradbury-Jones 2018: 8). Bila et al. (2015: 02) in similar vein, adds that people living with albinism get raped often because people think that sleeping with a person with albinism cures one's HIV and AIDS disease. In addition, Barker et al. (2010: 172) and Machoko (2013: 319) also confirm that people with albinism are attacked and raped because they are

used as means of healing the other people, including people with diabetes, HIV and AIDS and cancer. Before discussing the legal perspective of rape, the study first provides facts about HIV and AIDS. This is because it is important to prove that the beliefs are invalid and inconsistent. This virus cannot be cured, and as such, raping someone can never cure one's HIV and AIDS infection. As a result, people living with albinism are being raped because people want to cure their HIV and AIDS status.

The Criminal Law (Sexual Offences and Related Matters) Amendment Act 32 of 2007 (Sexual Offences Amendment Act) protects any person who has experienced any of the following:

Rape occurs when a person forces another to have sexual intercourse without their consent. This is a crime and must be reported. The Act also makes it a crime for a person to force another person to rape someone. This is known as compelled rape.

Sexual assault occurs when a person sexually violates another person without their consent. This is a crime and must be reported. The Act also makes it a crime for a person to force another person to witness or perform sexual acts to someone. This is known as compelled sexual assault.

According to Section 3 of the rape Act “any person who unlawfully and intentionally commits an act of sexual penetration with another person without the latter's consent, is guilty of the offence of rape” (As cited in Snyman 2014: 343). This means that people who forcefully have sexual intercourse with people living with albinism are actually committing a crime of rape which is unlawful in South Africa. As a result, perpetrators should be charged for their wrong doings. Matolino (2014), in limited communitarianism also advocates for the punishment of those who do wrong to others.

Another common believe surrounding albinism is that people beliefs that the body parts of people living with albinism can make good ingredients to make muti. There are people who think that the body parts of people living with albinism can be used to make strong *muthi*. The Under the Same Sun Report confirmed that the use of the body parts of people with albinism for *muthi* is part of a larger practice in the use of human body parts for *muthi*. This is as a result of the belief that raping people living with albinism can cure HIV/AIDS. In

Chapter two, there is a story of 13-year-old girl from Mpumalanga in South Africa who was killed because a traditional healer told a businessman that his business will flourish if he gets body parts of a person living with albinism. The story of Xolane Mkhize from Msogwabo in South Africa also made headlines. He was found with some of his body parts missing after he was buried. “His hands and foot were chopped of his body less than 24 hours after he was buried at the Tekwane north graveyard” (Enews :2018). It is believed that the perpetrators did this so they can make *muthi* from his body parts. Referring back to chapter two, it is important to note that killing people for the sake of *umuthi* is something common among African people, and majority of such killings are a result of certain beliefs surrounding a certain group of people, in this case, people with albinism. In the case of Xolane Mkhize, the violation of his body is just as immoral as violating a person who is alive. The deceased should be well-respected as it is believed that they should die in peace. Beliefs such as raping and killings of people living with albinism raise many questions including the very important question of why is it that other human beings will be killed for others to flourish.

The study refers to limited communitarianism, which asserts that there are some individual rights that should not be infringed upon. The thesis of limited communitarianism is closely related to the 1948 UN Declaration of Human Rights and section 10 of the South African Bill of Rights.

Limited communitarianism argues for the respect of persons for two reasons; firstly, because they are God’s creation; secondly, because human beings have rights that should not be violated. PWA are persons, hence, they are God’s creation, and for this alone, they deserve to be treated with dignity and respect in a similar way people without albinism are treated. With regards to the rights that cannot be violated, the study makes reference to the Universal Declaration of Human Rights and the Bill of Rights in the South Africans Constitution.

#### **4.2.4 PWA have the right to Mental and Emotional health**

Typically, traditional African people do not believe in things that are not tangible or that cannot be seen, for example, trauma. A traditional African person would never understand trauma and its effects on humans. Trauma is something that happens to a number of people, but they never get to understand what it truly is. People living with albinism suffer from trauma. This is because of the effects of the African traditional beliefs surrounding albinism. Below I will discuss what is trauma, what happens when a person is traumatized and the consequences of trauma. Fischer and Eiedesser (1999 as cited in Vedat Sar and Erdinc Ozturk 2006: 8) define trauma as follows:

Trauma is, in fact, an experience which is related to both the subjective and objective components of a situation, trauma is the experience of vital discrepancy between threatening factors in a situation and individual coping abilities. Moreover, trauma is not merely a situational phenomenon, but a longitudinal socio-psychological process which develops in time and follows a course.

As the above definition asserts, trauma is as a result of an experience resulting from an event that is not pleasant to an individual. Stressful life events such as the ones faced by people living with albinism cause PWA to suffer from trauma. This also negatively affects a person psychologically and hinders the psychological well-being or mental health of an individual. In a similar vein, Vedat Sar and Erdinc Ozturk (2006: 14) assert that “a traumatic experience interrupts the linear process of the complete psychological development throughout a person’s life”. Stories of what happens to people living with albinism are in the newspapers and on social media every now and again. This can also lead to trauma for persons living with albinism because they know such attacks can happen to them anytime. This also shows that even if a person living with albinism has not been attacked, they are traumatized by what they see and hear happening to other people living with albinism. A traumatic experience does not mean that a person has to personally go through a difficult event. Families of people with albinism are traumatized by what happens to their family members if attacked or killed.

#### **4.2.5 PWA have the right to be treated with respect**

PWA should not be discriminated against and should be respected for their humanity. In simple terms, discrimination can be defined as an action of pointing out differences in things, this can include skin color, race, religion or culture. This can be done intentionally or unintentionally. Cited in Fuegen and Biernat (2000:286) “The personal/group discrimination discrepancy refers to the phenomenon that members of groups who are potential targets of discrimination perceive a higher level of discrimination directed at their group as a whole than at themselves as individual members of that group (D. M. Taylor, Wright, Moghaddam, & Lalonde, 1990)”. To a certain extent, almost everyone can discriminate without being aware that they are discriminating. For instance, preferring one person over another because they have something in common with you, can be a form of discrimination. It is said that there are two types of discrimination, namely fair discrimination and unfair discrimination (Currie & De Waal 2013: 224). Fair discrimination is when someone benefits from a decision or that decision has a positive outcome. For example, if a job application clearly states that they are looking for people with disabilities or living with albinism, this is fair/positive discrimination because it ensures that people who were previously disadvantaged or overlooked are opened up to job opportunities. Whereas unfair discrimination is “discrimination with unfair impact” (Currie & De Waal 2013: 225). This study will look at unfair discrimination, section 9 subsection (3), (C) of the Bill of rights Currie and De Waal (2005: 246) mentions that:

Unfair discrimination has this impact where it imposes burdens on people who have been victims of past patterns of discrimination, such as women and black people, or where it impairs to a significant extent the fundamental dignity of the complainant.

People living with albinism are discriminated against. With reference to the belief that they are not human, it is evident that they are discriminated against. They are not seen as being part of the human species whereas they are, they are basically being discriminated for their physical appearance. This has led in them having difficulties when participating to daily activities such as going to shopping malls with people looking at them in a strange way.

With reference to what Imafidon (2017) calls the “the otherness”, this alone is proving that people living with albinism are not seen as part of the human species rather as the other.

The belief that they can cure HIV and AIDS means that they are seen not seen as human beings but as a means of curing human beings. From the above-mentioned belief, we can conclude that people living with albinism are used as means and discriminated against by the community because they are pigmented differently than others.

According to chapter 9 of the South African Bill of Rights, sub section 185 (1b) “to promote and develop peace, friendship, humanity, tolerance and national unity among cultural, religious and linguistic communities, on the basis of equality, non-discrimination and free association”. Imafidon asserts that “broadly construed, albinism is socially and culturally representation as an unwelcomed abnormality or difference, much the same way as other forms of disability are negatively designated in African tradition” (Imafidon 2017: 19). Meaning that African traditional people have a negative attitude towards things that they are not familiar with or something that is different from the norm. This is a form of discrimination. People living with albinism are discriminated against because they are perceived as different. Should this mean that they should not be regarded as humans just for the mere fact that they look different? This is immoral because no two people are the same. Yes, our pigmentation might be slightly dissimilar, but this does not mean we are not the same. Whether one is dark-skinned or light-skin, one is still considered human because we are not any different.

Another issue affecting people living with albinism and their families is grave robbery. Grave robbery is extracting the body from the grave without consent from the family. Typically, this takes place when perpetrators want to use body parts of the deceased. Grave robbery is when the body of the deceased is dug up from the grave in order to get the parts that they can make *umuthi* with. *Muthi* killings are common in African communities. This is discussed in detail in chapter two section 2.12.

Grave robbery is becoming common. Research has shown that there is an increase in the amount of cases where the graves of people living with albinism are dug up as a means of getting their body parts. The story of a 28-year-old Xolane Mkhize made headlines in South Africa. Somebody was found with his body parts missing less than 24 hours after his burial. It was said that his foot was chopped off and some of his body parts were missing (Under The Same Sun Report 2019:2). This action has become common especially when people

want the body parts of people living with albinism. In reports published by an NGO called UTSS, it was stated that there is an increase in the cases reported for grave robbery. Using Tanzania as an example, the amount of grave robberies reported in 2013 was 15, which saw an increase to 16 in 2015. A greater increase showed in 2019 which amounted to 24 reported grave robbery cases. There are two possible reasons for the above cases; the first possible reason is that they perhaps want to sell their body organs for PWA on the black market; Secondly, it is likely that they desire to use PWA's body parts to make *muthi*, which is the most common among the South African communities.

According to Synman (2014: 435) there are laws against the violation of graves and the corpses. This includes the following:

Violating a grave consists in the unlawfully and intentionally damaging a human grave.

Violating a corpse consists in the unlawfully and intentionally violating a corpse.

In South Africa, grave robbery is unlawful because it is the violation of a grave of a human being. It is known to everyone that a deceased person should be treated with respect and dignity. In the African community, a deceased person is treated with as much respect as possible because it is believed that as much as they are not present physically, their spirits live eternally and for them to live eternally they should be in peace. Similarly, the violation of corpses is unlawful for a number of reasons, one of which includes the traumatic experience that the family has to go through. People living with albinism should be respected and deserve dignity even after life.

Using limited communitarianism and the rights-based approach, it is evident that the African traditional beliefs surrounding albinism cannot be sustained or ascertained and it is therefore inconsistent.

### **4.3 Conclusion**

This chapter focus on presenting the analysis. The researcher has analysed the beliefs surrounding albinism using the ethical theory of limited communitarianism and the rights-based approach, which are closely related. This chapter has outlined the beliefs surrounding albinism and analysed them, it has also discussed the effects of the African traditional

beliefs surrounding albinism. The main issues noted from the above chapter is that people living with albinism are discriminated against and their human rights are violated upon. However, the researcher has proven that people living with albinism are human, this was done by making reference to the Akan and Yoruba scheme. As a result, they should not be socially excluded because they have the right to participate in the community. As noted above, PWA should not live in fear of being abducted or raped and their dignity should be respected even after death. Finally, PWA should be free and feel secure in their communities. It can be concluded that the beliefs discussed above are inconsistent and cannot be ascertained because evidence show that indeed people living with albinism are human. They are human beings because it is traceable that they are born of a mother and a father. The next chapter is the conclusion. It encompasses of the conclusion of the study, the summaries of the chapters as well as the researcher's recommendations.



## Chapter Five – Summary, Conclusion and Recommendations

*I have always known that deep down in every human heart, there is mercy and generosity. No one is born hating another person because of the color of their skin, or his background, or his religion. People must learn hate, and if they can learn to hate, they can be taught to love, for love comes more naturally to the human heart than its opposite. Even at the grimmest time in prison, when my comrades and I were punished to our limits, I would see a glimmer of humanity in one of the guards, perhaps just for a second, but it was enough to reassure me and keep me going. Man's goodness is a flame that can be hidden but never extinguished (Mandela 1994: 542).*

The above quotation are words of the globally acclaimed and well-respected man, Nelson Mandela. These words are valuable because they express the philosophy of Ubuntu. A lot can be learnt from the above statement. Firstly, Mandela asserts that humans are kind and compassionate. Secondly, he notes that love and hate are learnt behaviors and that love comes naturally. Two lessons can be drawn from this quotation and the phenomenon discussed in this dissertation. In the first place, the community can learn to be kind and generous towards people living with albinism. The community can learn to love and protect them as fellow human beings. Secondly, people living with albinism should learn to forgive the community for all the injustices that they have been made to go through, but most importantly we can all hope for a better tomorrow for the community and the people living with albinism.

### 5.0 Introduction

The previous chapter was the analysis. The key issues highlighted in that chapter were the beliefs surrounding albinism. The chapter analyzed the beliefs surrounding albinism through the lens of two theories, namely limited communitarianism and the rights-based approach. Chapter four also discussed the effects of the African traditional beliefs surrounding albinism. The chapter was concluded by showing that the African traditional beliefs surrounding albinism are inconsistent and they cannot be defended. As a result,

people living with albinism deserve to be treated with respect and dignity like all human beings.

This chapter is the concluding chapter of the dissertation. It includes a summary of the chapters. The main aim of this research was to explore the African traditional beliefs surrounding albinism in African communities in light of limited communitarianism and the rights-based approaches. Discourse on albinism among scholars has revealed that people living with albinism are socially excluded because they appear to be different from people born without albinism. In the context of South Africa, there is an increase in the amount of reported cases of violent attacks and killings of people living with albinism. Evidence shows that this is because the community is not well informed or educated about the disorder. Reports featured in the Under the Same Sun Report show that between December 2013 and May 2019, the amount of reported cases have increased to almost double of what it is was in 2013. As a result, the research conceived by the researcher was recommended for the South African communities to assist community members to evaluate, in order to rebuild their communitarian obligations to fellow human beings.

### **5.1 Summary**

Chapter one was the introductory chapter in which the outline of the study was given. The outline consisted of the objectives of the study, the main research question, the methodology, and a brief summary of the theoretical framework. It is important to note that the study was conducted using a desktop approach. Chapter one addressed key areas of the study. The entire study was motivated by a story which made headlines in South African media platforms between January and March 2018. This was the story of a 13-year-old girl who was abducted from her home and killed for her body parts as a means to enrich a businessman. This is what inspired the study's exploration and assessment of the African traditional beliefs surrounding albinism.

Chapter two was the literature review. Scholars have written on albinism from different disciplines some of which include law, anthropology, and the philosophical perspective. When seeking in-depth understanding on albinism, scholars such as John Makhumbe, Ester Hongs (2006), Alvis Imafidon (2017 and 2018 and 2019), Maureen Mswela ( 2013 and

2017), Melodie Nothling-Slabbert ( 2013) and Saweli (2011) are the main scholars that have written about this phenomenon, even though they have written from different perspectives. Alvis Imafidon has written a book from a philosophical perspective, explaining why people living with albinism are not accepted and seen as the other in African community. One of the main issues that came out of this chapter is the fact that there is an increase in the amount of people who have reported cases of violate attacks and murders towards people living with albinism. People living with albinism are attacked and killed for a number of reasons, this has resulted from myths and superstitions brought by the African tradition beliefs surrounding this phenomenon.

Chapter three outlined the theoretical framework used to guide the dissertation. It started with an introduction of the African theory of communitarianism, which helped to establish a foundation for the understanding of a person from the communitarian perspective. Communitarianism was briefly explained to mean a group of individuals with shared beliefs, living in harmony and in solidarity with one another. The three types of communitarianism namely, radical communitarianism, moderate communitarianism, and limited communitarianism were also explained. The values embedded in radical and moderate communitarianism were not able to meet the objective and aims of this study, as a result, limited communitarianism was selected as the type of communitarianism that best fitted the purpose of this study. Proposed by Bernard Matolino (2014), limited communitarianism is an ethical theory that puts emphasis on the importance of the individual over the community. This theory asserts that there are individual rights that can or should not be violated and that those who do wrong to others should be punished for it. Furthermore, limited communitarian theory deals with two types of identity namely, the metaphysical identity, which is also known as personal identity, and the social identity, which is the community's perception of who or what one must be. The shortcomings of limited communitarian theory were, in addition, discussed. It was suggested that Matolino should have included the ancestral lineage of persons in his attempt to find the African communitarian understanding of a person. In addition to this theory, the rights-based approach was used, particularly, the UN Universal Declaration of Human Rights and the

Bill of Rights found in the South African Constitution. This was done to examine the specific individual rights that cannot or should not be violated.

Chapter four is the analysis. This chapter analyzed the main themes derived from the literature review through the lens of the theoretical framework which was discussed in chapter three. This helped to explore the African traditional beliefs on people living with albinism and helped to attain my research objectives discussed in chapter one. A key issue that came out of this chapter is that the lives of persons living with albinism is negatively affected by the African traditional beliefs. In chapter four, the implications of the African traditional beliefs surrounding albinism were discussed. These include the community discriminating against people living with albinism, people living with albinism living in fear, the community killing and torturing people living with albinism. Chapter four also discussed the effects of the beliefs surrounding albinism. It also looked at the effects the beliefs have on people living with albinism and their families. People living with albinism are not only physically affected but also suffer mentally with all that is happening around them. Drawn from the effects of the African traditional beliefs surrounding albinism, it was shown that people living with albinism are not living a happy life. They are not living a life that human beings ought to live. Finally, it was noted that the government and community leaders have neglected this phenomenon.

## **5.2 Limitations**

The first limitation encountered by the study was time and resources. This influenced the study's choice for a desktop study approach. There is no doubt that the content and findings of the study would have been better informed if it was an empirical study. It would have gotten the study some insights from all the parties involved such as the community, the family and the people living with albinism.

## **5.3 The Recommendations.**

The findings of this study reveal that illiteracy among the people concerning albinism is one of the causes of the negative issues faced by people living with albinism in South Africa. Therefore, there is a need for awareness campaigns that can be effective and have an impact on the society. Campaigns that are influential and effective for example the HIV

and AIDS campaigns, something that will be open to all citizens and the availability of counselling for those affected. In South Africa, September is marked as albinism month. The problem is though is that, the people who know about this awareness month are people who are affected by this disorder and not all citizens. The study therefore recommends that a public holiday should be instituted during this awareness month, a holiday that would be observed by all the citizens. Like every other holiday, the day will be marked with campaigns for the rights of albinos, and we will have families of the deceased who were victims of attacks share stories as a way of making the society aware of how the myths and superstitions are harmful to those affected. There would be educational programs on television, commemorations organized by the government to put an emphasis on the rights that are violated by the attack, killings and stigmatization against people living with albinism. This study believes that through education the oppressed would be set free.

### **5.3.1 Education and awareness campaigns**

Education can simply be defined as the passing down of knowledge. It places an important role in the development of the country and its citizens. In chapter two, education is defined. For the sake of this recommendation it would be appropriate to use the word awareness and education interchangeably because, traditionally education is passed down in a formal manner, which is not the only form the study is referring to. The African traditional beliefs surrounding albinism show that people are unaware of what albinism truly is. I recommend that the community leaders and the government work together in implementing awareness campaigns to pass down knowledge about albinism. This can be done in community halls, in churches and workshops. It is important that these campaigns start with mothers of children living with albinism. Because albinism affects a minimal amount of the population, the mothers themselves need counselling because of the nature of their child. After the mother is made fully aware of the nature of the disorder, it is important that the family also gets knowledge about this disorder because sometimes a mother might happen to understand the disorder, but the families are unable to support the child because they see him/her, for example, as a “curse”.

The use of indigenous knowledge systems will also be of help to the community in understanding albinism in this regard since African people value what their elders teach

them. Indigenous knowledge System (IKS) is the traditional ways in which African people passed down knowledge. For example, knowledge was passed through proverbs, storytelling and folktales. IKS is important because it is usually in the language commonly used by that community or tribe, which makes it easy for them to comprehend. This form of education might be helpful because the younger generation will grow up knowing that albinism is a disorder, and that people living with albinism are just as human as people born without albinism.

In addition, the study recommends that the government should have facilities that are inclusive to people living with albinism. As mentioned in chapter one, people living with albinism have visual difficulties which is a barrier to their education. The study recommends that the department of education build schooling facilities that are user friendly to PWA. This will make sure that PWA are not disadvantaged in acquiring their education. This can also benefit learners without albinism but with visual difficulties. As has been discussed in chapter two, road drives are a form of informal education. Road drives are done to educate the community through awareness campaigns. This form of education is effective because usually, people learn through having fun. It can be in a language that is most understood by the community, and the invitation of public figures will be of benefit.

Having focus groups will also be of benefit. By Focus groups I mean that there are specifically some people who need to be educated on albinism. These include traditional healers, such as *sangomas*. This is because they need to be taught that albinism is a pigmentation of the skin, and that there is nothing magical about it. The issues about using the body parts of people with albinism starts with the traditional healers and *sangomas* because they are the ones that send people to the community to attack people living with albinism. Referring to the story that motivated the study also included in the appendices, it is reported that the man who killed the Gabisile Shabane was advised by a traditional healer to get body parts of a person living with albinism so that he can flourish. As a result, it is important that *Sangomas* get education about albinism because they have a major influence in the killings and attacks of people living with albinism.

### **5.3.2 Inclusion of the rights of people living with albinism in the South African legislation**

Legislation is the principles or laws that the citizens of a country abide by. In South Africa, the legislator, who are the people in parliaments, municipal councils, gather and discuss laws that should be made for the country. There is a need for the S.A government to pass legislation that will be inclusive of PWA. The definition of the legislation and its importance has been discussed in detail in chapter two.

It is recommended that the above policy makers of South Africa include laws in the Bill of Rights or in the Constitution that directly speak to issues faced by people living with albinism in a similar way that they have laws that speak to issues of race, gender and rape. They should implement policies that specifically look at albinism. People living with disability are protected by the law which has opened opportunities for them such as education and employment. The inclusion of people living with albinism in the South African Legislation will emphasize the importance of respecting and protecting them. This will also ensure that those who violate and attack people living with albinism are punished for their wrong doings. It appears the perpetrators are not taking these crimes seriously because it looks like the government is not paying specific attention to issues faced by people living with albinism.

Issues affecting people living with albinism should also be part of African customary laws, for two reasons. Firstly, it is an issue affecting African people and secondly, African traditional people take their own laws seriously more than they take the Constitution and the Bill of Rights. African traditional people, especially the elderly, find it hard to adapt to something new, hence, having laws in accordance to their culture will be of benefit to them. In South Africa, there is a structure called the Institution of Traditional Leadership where kings and chiefs of African communities gather to discuss issues affecting people in the community and to pass laws that are directly for the African community. Such structures will benefit people living with albinism, because as mentioned in chapter two, traditional people respect their kings and chiefs more than they do their government and its structures. For example, when it comes to circumcision, the government has provided means to offer medical circumcision as opposed to traditional circumcision because the traditional one

has more negative consequences such as the risk of fast spreading HIV and AIDS. Despite this, in rural areas, people still prefer doing it the traditional way. They, for example, will send their young men to the mountain and get them circumcised in the mountains. They do this because they believe that young men should go through the traditional circumcision in order to have a successful initiation ceremony. However, if there was a law passed against the practice by the royal house, they will be forced to abandon the practice.

### **5.3.3 Political participation**

Political parties have the duty to encourage people living with albinism to be active members of political parties. It would be good to see a PWA being a Minister of health, being a premier, major or any other high position as a political member. This will help the community familiarize themselves with them. Such involvement might also help this vulnerable group of people get advocacy and protection. Having PWA playing roles in the community will help the community members see that they are human beings and that albinism is a disorder and nothing more. As a result, the community can have people living with albinism as role models and people they look up to. Government structures should have a budget that will assist NGOs and institutions that deal with issues of albinism for it is difficult to campaign and create awareness programmes if there are no funds available for the organizations.

### **5.3.4 Public Holiday**

Public holidays are days set aside for people not to go to work and observe an event. In most cases, it is to celebrate a struggle that people went through in the past. Having a public holiday called albinism day will have a significant impact in the understanding of the disorder. This is because under normal circumstances, during a public holiday, people celebrate a phenomenon. For example, on June 16, which is a day to remember and celebrate all those school children who died in the protest in Soweto, South Africa. On this day, documentaries of what transpired in Soweto are shown on Television and media platforms, the younger generation are educated on what happened on June 16 and the significance of this day. In a similar way, albinism day can be a day where families of the deceased may share stories about how their loved ones who were killed for living with



albinism lived and died. During this holiday, television programs will be campaigning for the rights of people living with albinism.

### **5.3.5 Duties of government and the community**

With these theories born in mind, one needs to consider the duties and obligation of the government, community and the family towards people living with albinism. The state has a duty to respect, protect, promote and fulfil the rights contained in the Bill of Rights (Mswela, 2017:118). This means that the government has the obligation to make it their responsibility that persons living with albinism are protected and that they receive as much respect as any other citizen receives. In the same manner that the government is providing for the rights for the poor, there should also be measure implemented so that the protection and the right to life is bestowed at birth to people living with albinism just like any other citizen of this country. There is also a need for education about this phenomenon. Government has the responsibility to ensure that there are serious and effective means of making sure that people living with albinism are fully incorporated as full members of the society.

The community and the family included also have a role to play. African communities believe in Ubuntu. Ubuntu means humanness. The community is therefore obligated to treat the other with Ubuntu, putting respect at the forefront. Before the implementation of human rights laws, Africans were taught to treat the other with respect. Therefore, it is time that South Africa brings back the values of Ubuntu when looking at the phenomena of albinism, they need to be respected for their humanity, and deserve social inclusion. “Your pain is my pain” is a common saying in South Africa so, after all the people who were killed and were attacked, this is a call on all to remember that the pain of the mothers whose children have been brutally killed is also our pain.

### **5.4 Conclusion**

This study has covered the issues associated with people living with albinism in South African communities. The study conducted a literature review in chapter two and found that there is a gap, which is a lack of adequate literature based in South African communities that looks at this phenomenon from a moral perspective. The study looked at

the beliefs, myths and superstitions surrounding albinism and the impact it has on the people that are affected. This study looked at this phenomenon from a moral perspective. The study made use of the rights-based approach and the ethical theory of limited communitarianism, which is primarily based on the social theory as a contract agreed upon by a group of people, and the Africa communitarian theory. One must note that rights are used to protect an individual from what may seem to be harmful and undesirable to that individual. Using the rights theory and limited communitarianism, the study has made use of the Bill of Rights of South Africa, which is found in the 1996 Constitution of the Republic of South African. The study discovered that the beliefs, myths, superstitions, killings, and violent attacks against people living with albinism violates the rights of people living with albinism.

The lack of knowledge about this condition is the main reason why people living with albinism suffer from social exclusion. This study also discovered that there is a need for awareness campaigns that will educate the community about this disorder. This is because the misconceptions about the disorder have given people different ideas about this disorder, leading to the myths and superstitions and the infringement and violation of the rights of people living with albinism.

People living with albinism are vulnerable citizens, they live in fear of being attacked and killed for their body parts. With the condition affecting a minimal percentage of the human population, the African community does not perceive them as human beings due to the beliefs surrounding this phenomenon, which has led to the myths and misconceptions about people living with albinism. Using the Akan and Yoruba conceptual schemes of the constituent of a person, this study has discovered that the negative and discriminatory beliefs about people living with albinism are inconsistent and invalid. The study ascertained that there are African traditional beliefs surround albinism, hence, there are negative effects on the life of persons living with albinism and their families, as discussed in chapter four. As a result, the study explored the theory of limited communitarianism and the rights-based approach to describe how the African traditional beliefs lead to negative effects for persons living with albinism and their families.

To conclude, the African traditional beliefs surrounding albinism are not true for two main reasons: 1) they are inconsistent and 2) cannot be scientifically or medically proven. African people tend to resort to speculations about things that they do not understand. It is the society that constructs ideas about a phenomenon that becomes the reality of that phenomenon. For example, the beliefs about albinism have been constructed by the community due to illiteracy causing ignorance about the phenomenon, which has caused these beliefs to become the reality of PWA. People living with albinism do not disappear instead, their bodies get stolen because people want their body parts for *muthi* to flourish their lives. People living with albinism are human because they are born of a mother and a father, they have traceable ancestral lineage, and they have traits of human beings. Albinism is a disorder which lacks the pigmentation of the eyes, hair and eye brow, as mentioned in chapter two. PWA are humans and have rights like all other human beings as declared in the Universal Declaration of Human rights, and in the constitution of South Africa. It is our duty as the community to live in solidarity and in harmony and show them Ubuntu as embedded in the values of an African community. This can be done through the involvement of the government working together with chiefs and educating the community as well as promoting the rights of PWA.

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## APPENDICES

APPENDIX 1: Article about Gabisiles killing

APPENDIX 2: Article on the Zulu King on Albinism

APPENDIX 3: Under The Same Sun Reports

APPENDIX 4: Ethical clearance

APPENDIX 1: Article about Gabisile's killing

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## APPENDIX 3: Under The Same Sun Reports

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