



**UNIVERSITY OF  
ZULULAND**

*A NODE FOR AFRICAN THOUGHT*

**Development of Intervention Strategies to Address the Abuse and  
Brutal Killing of People with Albinism in KwaZulu-Natal**

**By**

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## DECLARATION

I, Mbongeni M. Shabalala, (20010288), declare that the thesis entitled **“Development of Intervention Strategies to address the abuse and brutal killing of PWA in KwaZulu-Natal**, is the result of my independent investigation and that all the sources have been acknowledged by means of references. I hereby certify that this thesis has not been submitted for any other degree.

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Signature.....  ..... Date January 2023

## DEDICATION

This thesis is first and foremost dedicated to the Almighty God: “Blessed is the man that walketh not in the counsel of the ungodly, nor standeth in the way of sinners, nor sitteth in the seat of the scornful. But his delight is in the law of the LORD; and in his law doth he meditates day and night. And he shall be like a tree planted by the rivers of water, that bringeth forth his fruit in his season; his leaf also shall not wither; and whatsoever he doeth shall prosper. The ungodly are not so: but are like the chaff which the wind driveth away. Therefore, the ungodly shall not stand in the judgment, nor sinners in the congregation of the righteous. For the LORD knoweth the way of the righteous: but the way of the ungodly shall perish” (Psalms 1:1-6).

I also dedicate this work to my lovely, beautiful wife Philisiwe Princess Shabalala and my lovely daughter and sons Ziphezinhle Zenkosi Shabalala, Okuhlenomusa Joshua Yahwe and Caleb Uyizwile Shabalala respectively, who have been by my side throughout this period and who without knowing it, have always stimulated me and given me the strength to carry on.

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## **ABSTRACT**

This phenomenological qualitative study's aim was to recommend intervention strategies to address the abuse and brutal killing of People with Albinism (PWA) in KwaZulu-Natal, based on the participants' (PWA and social workers) experiences and knowledge. Interest in this study was triggered by the researcher's interactions with PWA, while rendering counselling to them due to their experience of abuse or witnessing or hearing about the brutal killings of other PWA. In addition, the continuous media coverage and observation of PWA being abused, murdered, stigmatised and marginalised by community members and strangers highlight the gross violation of a vulnerable group of people. The study was underpinned by two theoretical frameworks which are namely ecological systems theory and resilience theory.

The sample included twenty-six PWA and ten (10) social workers, who had two years or more experience of counselling PWA who had in turn experienced, observed or heard about the abuse and killing of PWA. The study was conducted in two municipalities in KwaZulu- Natal, South Africa, namely eThekweni Metropolitan and uMgungundlovu District Municipality.

In-depth, semi-structured interviews were conducted to explore the participants' experiences, perceptions, observations and opinions on the abuse and brutal killing of PWA to recommend intervention strategies to address this scourge. Data was analysed using thematic analysis.

Social workers and people with albinism agreed that people with albinism are abused and brutally murdered. The study findings revealed that among the people with albinism who were interviewed, there were those who had experienced abuse from the public and those who witnessed abuse. The study findings also showed that people with albinism are abused in many different ways. One of the key abuses is that people with albinism are discriminated

against because of their skin colour and are labelled with different names. The study findings showed that people with albinism usually suffer from emotional, physical and sexual abuse, as well as possible killing. The findings highlighted several factors contributing to the abuse and brutal killing of PWA. These factors are not limited to a lack of awareness, cultural beliefs and practices, as well as inadequate knowledge of people with albinism. It was revealed that the body parts of people with albinism are believed to be a useful solution in healing and bringing fortune to one's life.

The findings of the study have refuted claims that having sexual intercourse with a person with albinism eliminates or cures those infected with HIV/ or AIDS. Despite the fact that people with albinism are living in fear, the findings of the study showed that they have very strong support from family members and teachers who provide them with first-aid help. The study concluded that the reason serious cases of abuse of people with albinism are known is because such cases are reported to social workers, police-stations, families and neighbours as well as schools. Finally, the study findings highlighted several roles that social workers play in an attempt to provide counselling to those who have experienced abuse and those who have witnessed it. Several intervention strategies were made which are not limited to a need for government to be fully involved in raising awareness of the abuse of people with albinism, educating the public about the wrong act of abusing people with albinism. The study also recommended that social workers needed to be fully versed on cases of abuse and murder of people with albinism. The full thesis is available in the University of Zululand Institutional Repository and other publications from the thesis.

**KEYWORDS:** Abuse; killing; albinism; KwaZulu-Natal, murder, PWA, United Nations

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## LIST OF ABBREVIATIONS

AIDS	Acquired Immunodeficiency Syndrome
IAA	International Albinism Awareness
HIV	Human Immunodeficiency Virus
IBA	International Bar Association
IDP	Integrated Development Planning
NGO	Non-Governmental Organization
NOAH	National Organisation for Albinism and Hypopigmentation
OA	Ocular Albinism
OCA	Oculocutaneous Albinism
OHCHR	Office of the United Nations High Commissioner for Human Rights
PWA	People With Albinism
SDGs	Sustainable Development Goals
SSA	Sub-Saharan Africa
SASSA	South African Social Security Agency
UDHR	Universal Declaration of Human Rights
UN	United Nations
UTSS	Under The Same Sun
UPIAS	Union of the Physically Impaired Against Segregation
UK	United Kingdom
UN	United Nations
UNESCO	United Nations Education and Scientific Organisation
USA	United States of America
WHO	World Health Organisation

## CHAPTER 1: ORIENTATION TO THE STUDY

### 1.1 INTRODUCTION

Globally, people with albinism (PWA) are confronted with a multiplicity of challenges, including abuse and brutal murder (Mwiba, 2019). Excerpts like those of Ikponwosa Ero, in Figure 1.1. below, continue to dominate visual, and oral local, national and international media and social media reports and demonstrate the marginalisation, discrimination, abuse and murder of PWA in South Africa and globally.



**Figure 1-1: Ikponwosa Ero, an independent expert on the enjoyment of human rights by persons with albinism, on the Niger River in Bamako, Mali.**

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*I was born in Nigeria, and I couldn't walk the streets without being subjected to abuse and cruel remarks and songs for having albinism. I used to question why I had been born in the first place. My mother comforted me by assuring me that God made no mistakes and that I was perfect as I was. Recalling my youth during a conference in Nairobi, I spoke of how often I was beaten in school, because I told the teachers that I could not see, and the teachers thought I was lying. I got through school by getting another student to copy the exam questions from the chalkboard in exchange for the answers. I went on to become a lawyer in Canada and in 2015, the United Nations Expert on Albinism, a post I still hold to date.*

Consequently, the Covid-19 pandemic has, to great extent, resulted in PWA being further discriminated against, abused and murdered (Amnesty International, 2020). Such discrimination, abuse and murder constitute a human travesty, violation and tragedy which warrants global attention and action. Hence, this research study aim was to develop intervention strategies to address the abuse and brutal killing of PWA in KwaZulu-Natal (KZN), South Africa. This chapter contains an introductory background, the problem statement, the study's aim, objectives and research questions, significance of the study, summarised literature review, theoretical framework, research methodology, and the structure of the thesis.

## **1.2 BACKGROUND OF THE STUDY**

Albinism is “a non-contagious genetically inherited condition” evident in babies and individuals of all genders, ethnicities, races, cultures and religions globally (Benyah, 2017; Kromberg, Manga & Kerr, 2020). It is estimated that globally, one in every 17 000 people has some type of albinism (United Nations, 2022). Within the South African context, an estimated one in 3 900 Black Africans have a type of albinism (Kromberg, Manga & Kerr, 2020). The incidence of albinism within the White population is reported to be much lower with an incidence rate of one in 15 000. In African countries, it is estimated that one out of every 4 000 people are born with albinism (Uromi, 2014).

People with Albinism have been exposed to discrimination in many countries, especially in Africa (Pooe-Money more, Mavundla & Christianson, 2012). The Harvard Gazette (2010) stated that they are considered outcasts in many societies and are not allowed to socialise or interact with people who do not have albinism. Most African people believe that albinism is a sign of punishment by God and that PWA have been cursed by God (Franklin, Lund, Bradbury-Jones, et al.,

2018). The stigmatising attitudes towards PWA is to a great extent due to ignorance surrounding albinism (United Nations, 2017).

The researcher noted with concern that people with albinism were not considered as human beings as their body parts are used for various reasons such as charms, fortunes and as medicine in African countries, including South Africa. In that light, this study sought to uncover how people with albinism can be treated like human beings rather than being abused or murdered given the situation that they are butchered and massacred while their organs are used as medicine (Mswela, 2013).

People with albinism experience societal, personal, communal, health, educational and societal challenges which warrant further investigation. Hence, in light of the above discussions, this study attempted to investigate the factors contributing to the abused killing of people with albinism in the province of KwaZulu-Natal in South Africa to develop integrated and systematic intervention strategies to address these attempts of abuse and murder.

### **1.3 PROBLEM STATEMENT**

The high prevalence of murder, abuse, forced amputations and the sale and trafficking of the human body parts of PWA is a global concern as such acts demonise and dehumanise human dignity and the human body. However, elevated statistics within the African context are more widely reported, with studies conducted in Africa highlighting the abuse and murder of PWA. Such acts are more pronounced in Tanzania, Malawi, Zimbabwe, Zambia and South Africa (Cruz-Inigo, Ladizinski, & Sethi, 2011; Masanja, Mvena, & Kayunze, 2015; Baker, 2018). In addition, media reports and research studies conducted on these abuse and killings occurring in South Africa is a growing concern (Cele, 2016; Mabona, 2018; Mswela, 2017). Mabona (2018) reported that many cases of abuse, and the murder and sale of PWA body parts occur in the province of KwaZulu-Natal (KZN), which is the study setting for this study. Furthermore, Cele (2016) reported that cases of abduction, rape and witchcraft are exacted by African people against PWA. These cases of abuse are also reported

throughout Africa with several studies focusing on the existence and causes of abuse of PWA (Mswela, 2013; Cele, 2016; Uromi, 2014). However, to the best of the researcher's knowledge, the development of intervention strategies to address the abuse and killing of PWA in KZN has not been conducted. Hence, this study fills a literature gap on the phenomenon.

The researcher's interest in the topic was motivated when he worked as a social worker at Benedictine Hospital in the province of KwaZulu-Natal for several years when he was providing counselling to clients with varying needs and challenges. While there, he observed that after counselling clients with albinism, many returned for subsequent counselling due to a lack of social intervention strategies and guidelines that adequately addressed the abuse and brutal murdering of PWA. Moreover, they reported cases of trauma, and emotional and physical abuse due to PWA body parts being harvested for medicinal purposes so that illnesses of others could be cured, to win court cases and elections and for good luck and favour. It is in this light, that the researcher planned to uncover and evaluate social factors associated with the abuse and killings of PWA in KZN to develop an intervention strategy that can reduce and/or eliminate the abuse and brutal killing of PWA. Despite the fact that there are no current statistics on the number of PWA who are murdered and abused on a yearly basis, Mswela (2017) stated that several cases of abuse and murder of PWA have been reported in South Africa.

#### **1.4 AIM**

The aim of the study was to develop intervention strategies to address the abuse and brutal killings of people with albinism in KwaZulu-Natal, South Africa.

#### **1.5 OBJECTIVES OF THE STUDY**

- A. To determine the factors contributing to the abuse and brutal killing of people with albinism in KwaZulu-Natal.
- B. To identify the coping strategies of people with albinism after hearing

- about, experiencing, witnessing or observing the abuse or killing of PWA.
- C. To describe the intervention strategies currently in place to combat and prevent the abuse and brutal killing of people with albinism in KwaZulu-Natal.
  - D. To develop intervention strategies to combat and prevent the abuse and brutal killing of people with albinism in KwaZulu-Natal.

## **1.6 RESEARCH QUESTIONS**

The study aimed to answer the following questions:

- A. What are the factors that contribute to the abuse and brutal killing of people with albinism in KwaZulu-Natal?
- B. How do people with albinism cope after hearing about, experiencing, witnessing or observing the abuse or killing of PWA?
- C. What intervention strategies are currently in place to combat and prevent the abuse and brutal killing of people with albinism in KwaZulu-Natal?
- D. What recommendations can be made to develop intervention strategies to combat and prevent the abuse and brutal killing of people with albinism in KwaZulu-Natal?

## **1.7 SIGNIFICANCE OF THE STUDY**

The study identified the factors contributing to the abuse and brutal killing of PWA, their coping strategies to deal with these violations of their human rights, and the current interventional strategies in place in KZN to develop interventional strategies to reduce and eliminate such practices. The findings will contribute to the improvement of existing South African programmes, interventions and policies to accommodate all South Africans, regardless of colour, gender, sex, race and ethnic group. The study is positioned in the era of the United Nations Sustainable Development Goals (SDG) which aims to be inclusive by *leaving no one behind*, including people with albinism. The SDGs, together with the 2030 Agendas, aim to realise a world free of poverty,

inequality, fear, discrimination, violence is particularly relevant for this study. The study objectives are supported by the SDGs reason being that the people with albinism are experiencing all forms of abuse from the public. The SDGs is against inequality, discrimination and violence against one another, and this study also wants to come up with intervention strategies to eliminate the abuse against people with albinism. In simpler form, the SDG supports the aim of this study and its research objectives.

As previously mentioned, the researcher is a social worker who has dealt with cases of abuse and the murder of PWA without any intervention guidelines. Therefore, this study's findings could be used by social workers to familiarise and equip themselves on matters regarding the abuse and killing of PWA. On completion of the research study, the researcher will present the findings to social workers with the hope of empowering them to strengthen their counselling skills. The study findings will be available through universities and social work departments for the benefit of KwaZulu-Natal communities. Additionally, the study will add to the body of knowledge on albinism with specific emphasis on the abuse and brutal killings of PWA due to the scarcity of such available information. Furthermore, the study findings and recommendations will be disseminated to benefit South African PWA and PWA located in global communities. As this phenomenon is not widely researched, this study's findings will benefit social workers and their practice. The findings will be disseminated and made available through journal publications, workshops and presented at national and international conferences.

## **1.8 LITERATURE REVIEW**

The literature review for the study consisted of information from various sources including e-journals, e-books, printed books and journals, findings of primary studies, scoping and systematic reviews and other information synthesis knowledge banks, magazines, newspapers, as well as South African and international policies, programmes and interventions. Moreover, the study accessed databases such Ebscohost, Emerald, Google Scholar, SA e-publications, SABINET, to mention a few. The internet was accessed due to it housing many sources of information.

It must be mentioned that the literature review was comprised sections that have been assigned headings and subheadings. Firstly, the study reviewed literature with the aim of providing a comprehensive overview of PWA, legislation applicable to PWA, their rights and the types of abuse, the factors contributing to PWA being abused and murdered and their coping strategies. The study primarily focuses on the abuse and killing of PWA in the province of KwaZulu-Natal. It also addressed the negative impact of abuse against PWA in KwaZulu-Natal. Lastly, it explored existing interventional strategies aimed at reducing and combating the abuse and murder of PWAs. In-depth literature on the topic under study is discussed in Chapter two.

## **1.9 THEORETICAL FRAMEWORK**

A theoretical framework facilitated and supported the theory guiding the research study by describing and explaining the theory or theories used in the study. Theories frame the concepts, assumptions and phenomenon in which they are embedded (Kumar, 2014). The study has utilised the Ecological Systems Theory and the Resilience Theory, which are explained below:

### **1.9.1 Ecological Systems Theory**

The Ecological Systems Theory was considered as appropriate to understand PWA experiences of abuse and brutal killing in KZN. This theory was developed by Urie Bronfenbrenner (1977) and is also referred to as the human ecology theory and development in context. The five environmental systems included in this theory are: the individual, the microsystem, mesosystem, exosystem and the macrosystem. Individuals can interact with all four systems. The theory is able to demonstrate how people relate, interact and treat one another within communities and environments and highlights the impact of these systems on individuals (Johnson, 2008). Community psychologists involved with the relationships of people within their communities, use this theory (Bronfenbrenner, 1977). Bronfenbrenner's four ecological systems have successfully been used in the context of PWA and the trafficking of body parts

previously.

In light of the above, the study used the Ecological Systems Theory as it enabled the exposure of the brutal killings and abuse of PWA, and how they relate and how others relate to them. Moreover, it allowed for a comprehensive analysis of how PWA's interactions result in gruesome murders, abuse and discrimination. Furthermore, the Ecological Systems Theory assisted in facilitated intervention strategies for the challenges faced by PWA.

### **1.9.2 Resilience Theory**

The Resilience Theory also frames the study and is rooted in adversity studies and the impact of various forms of adversity on the lives and well-being of PWA. This study is located in the social work discipline, which facilitates change. The global definition of social work is: "Social work is a practice-based profession and an academic discipline that promotes social change and development, social cohesion, and the empowerment and liberation of people". This definition reinforces the change component of the profession and the ability of social workers to be agents of change and to guide clients to also be change agents. The second objective and research question addressed the coping skills and strategies that PWA use or implement regarding the abuse and brutal killing of PWA. Hence, the relevance of the inclusion of this theory. The two theoretical frameworks adopted for the study namely, the Ecological Systems Theory and the Resilience Theory are discussed in greater depth in Chapters three.

## **1.10 RESEARCH METHODOLOGY**

Research Methodology is a strategy of action articulating the logical and sequential steps of how the study addresses and adequately responds and answers the research questions (Kumar, 2014). This study embraced a qualitative, phenomenological, interpretivism research paradigm. Data was collected from 26 semi-structured interviews with PWA and 10 social workers who had worked with PWA in the eThekweni Metropolitan and uMgungundlovu District Municipality located in the province of KwaZulu-Natal for two years and more. The research methodology used in the study

will be discussed in more depth in Chapter 4.

## **1.11 RELEVANT LANGUAGE AND TITLE**

With regard to the non-use of the word *albino* and the term *People Living with Albinism*, the term “*albino*” will not be used in this thesis as it is discriminatory and offensive to PWA as the term refers to the condition rather than the person who has albinism. PWA, or persons with albinism, is preferred as it opines that the people lead by being in the forefront, with the condition following. Hence, in this thesis, *PWA* or the acronym, *PWA* is used due to the PWA who participated in the interview pilot test, advising the researcher that *albino* and *people living with albinism* was unacceptable - to them, as they were born with albinism, they did not have a choice.

## **1.12 DEFINITION OF KEY TERMS**

### **1.12.1 Albinism**

According to the Mayo Clinic (2022), albinism is defined as an inherited condition whereby a person is unable to produce normal colouring of the skin, hair and eyes (lack of pigments). However, in this study, the term albinism refers to human albinism and will mean all people who have pigment challenges and the colouring of their skin, hair, eyes, feet and hair are affected.

### **1.12.2 Human Albinism**

Albinism is a term that is used to describe a group of medical conditions, which are because of a recessive genetic mutation. As a result of this recessive gene, persons with albinism have lack of, or deficiency of, pigmentation, known as melanin (McLeod, 2010).

### **1.12.3 Experiences**

According to the Mayo Clinic (2022), the word experience means when someone experiences a particular situation or is in that situation and it happens to affect him or her. In this study, experiences mean what PWA are going through in the society in which they live.

### **1.12.4 Evaluation**

Evaluation refers to judgments made about projects, systems and processes in endeavours to make a final decision on the potential, success and challenges of these. In this study, evaluation refers to how PWA cope after experiencing abuse and/or observing and hearing about the murder of PWAs.

### **1.12.5 Environmental Factors**

Environmental factors refer to the factors that contribute and predispose PWA to being at risk of abuse or murder. These factors include crime, unemployment, community members' behaviours, attitudes and poverty.

### **1.12.6 Ocular Albinism (OA)**

Ocular albinism is a type of the genetically-inherited disorder in human albinism which predominantly affects individuals' eyes due to melanin-deficiencies and their inability to produce adequate amounts of the melanin pigment. The nerves behind the PWA's eyes and their retinas are affected, resulting in vision challenges including sunlight sensitivity, visual acuity and involuntary rapid eye movement.

### **1.12.7 Oculocutaneous Albinism (OCA)**

This is the most common and prevalent type of albinism in Southern Africa. Individuals

with this type of albinism have lighter than normal coloured hair, skin and eyes and have patches on their skin without colour (Gaigher et al., 2002). m.

### **1.12.8 Person(s) Living with Albinism (PLWA)**

This term refers to individual(s) who have the condition of albinism. According to Berger et al. (2011), researchers should avoid using dehumanising language when referring to persons with any form of illness or disability. When reporting on research participants, researchers should rather aim to use person-centred language. The National Organisation for Albinism and Hypopigmentation (2021) recommended that using the term person(s) living with albinism places the individual/person first rather than their condition. Though several terms are used, namely PWA, person(s) living with albinism, person(s) living with albinism and people living with albinism, the term people with albinism and the acronym PWA is primarily used in this study as the pilot participants and study participants requested that PWA be used as they were most comfortable with that term and acronym.

### **1.12.9 Social Identity**

Social identity refers to “that part of the individual’s self-concept which is derived from his/her knowledge of his/her membership of a social group, together with the value and emotional significance attached to that group” (Treppe, 2006:259).

### **1.12.10 Stigma**

Stigma refers to “an attribute that extensively discredits an individual, reducing him or her from a whole and usual person to a tainted, discounted one” (Goffman, 1963:3). Similarly, stigma is a social construct levelled at individuals who are considered different to others, devalued as a result and positioned and located at the epicentre of the breakdown and fragmentation of social relations and psychological wellbeing (Brocco, 2016). Such devaluing of PWA may result in social and financial exclusion.

Stigma experienced by the participants is articulated in the findings of this study.

#### **1.12.11 Myths**

Myths refers to "... man-made stories that play explanatory functions in the African understanding of reality" (Jaja, 2014:9). Within this study, myths refer to misrepresentations and perceptions of PWA.

#### **1.12.12 Normals**

Normals refer to "persons who don't have an undesirable characteristic and who are considered to be normal according to social standards" (Goffman, 1963:5). Individuals who differ from normals may be stigmatised, ostracised, marginalised, discriminated against and devalued. In the context of PWA, people without albinism may stigmatise, discriminate against, abuse or even murder PWA due to a lack of awareness of the condition.

#### **1.12.13 Nystagmus**

Nystagmus is the involuntary back-and-forth movement of the eyes. Otherness/othering describes "a discursive process where a dominant in-group constructs one or many dominated out-groups by stigmatising a difference and presenting it as a negation of identity and motive for potential discrimination" (Staszak, 2008:2). Othering in the context of this study is relevant as it highlights how PWA are constructed, labelled, stigmatised and marginalised.

#### **1.12.14 Strabismus**

Strabismus refers to crossed eyes or "lazy" eyes (Cancer Association of South Africa (CANSAs), 2021).

### **1.12.15 Diviner (iSangoma)**

A diviner (iSangoma) is a traditional healer who uses prophecy mostly for therapeutic purposes and is also a fortune teller. It is worth noting that a diviner (iSangoma) may treat and control ailments as well as cast away evil spirits using medicinal plants and animal parts. Diviners are frequently used to connect the living with the dead. In other words, they are spiritual healers who use rituals and prayer to connect living people with their ancestors (Pretorius, 1999).

### **1.12.16 Concoction (muti)**

A concoction is considered as a combination of knowledge and practice used in diagnosing, preventing, and eliminating disease. More specifically, a concoction (muti) is a combination of herbal medicines and animal parts that are used to treat and manage ailments or expel evil spirits. Important to note is that this kind of concoction (muti) is highly associated with traditional healers (Mokgobi, 2014).

## **1.13 STRUCTURE OF THE THESIS**

The thesis contains preliminaries, including the title page, declaration, acknowledgements, dedication, abstract, table of contents, list of tables/ figures, abbreviations and acronyms, and list of appendices as well as a breakdown of each chapter.

### **Chapter 1: Introduction**

Chapter 1 introduces the study and provides the conceptual and contextual settings of the study; problem statement; aims, objectives and research questions; motivation; significance; a summary of the literature review; research methodology, scope and limitations of the study; dissemination of results; and definition of terms and the structure of the thesis.

## **Chapter 2: Literature Review**

The literature informing this study is discussed in this chapter

## **Chapter 3: Theoretical Framework**

The theories framing this study and their relevance to the study are explored in this chapter.

## **Chapter 4: Research Methodology**

This chapter provides information regarding the study, aim, objective and research questions, research paradigm, approach, design, study sites, study population, sampling, study sample, inclusion and exclusion criteria, recruitment strategy, data collection, data analysis, trustworthiness and ethical considerations.

## **Chapter 5: Findings**

Includes a presentation of the study's collected data, data analysis and interpretations thereof.

## **Chapter 6: Concluding Chapter**

This chapter summarises the findings, presents conclusions, recommendations and narratives.

## **CHAPTER 2: LITERATURE REVIEW**

### **2.1 INTRODUCTION**

The intention of this chapter is to provide a comprehensive literature review of the phenomenon (the abuse and killing of PWA) under study. A literature review is an exposé of research conducted and published on a topic by accredited scholars and researchers to convey to the readers the range and depth of knowledge and ideas on a topic, and the strengths and weaknesses of such scholarship (Pautasso, 2013). It is guided by the research aim, objectives and questions, the problem or issues under discussion and does not merely contain a descriptive list or summary of literature. A literature review enlarges the knowledge base of a phenomenon and allows the researcher to improve and demonstrate skills in other areas (Fry, Scammell & Barker, 2017).

In this study's thematic literature review chapter, an overview of albinism, the types of abuse levelled against PWA, factors contributing to the abuse and killing, their coping strategies and intervention strategies aimed at preventing the abuse and killing of PWA is also provided. The chapter concludes with a summary of the lessons learned and how this research project aimed to fill research gaps to facilitate an environment where PWA feel respected, protected and safe.

### **2.2 ALBINISM**

Albinism occurs in animals and humans, however, this study focused on human albinism. The word "albinism" originated from *albus* a Latin word meaning *white* (Federico & Krishnamurthy, 2020). This genetically transmitted condition is passed on from parents who give the albinism gene to their babies and is no respecter of person as it occurs in babies globally, irrespective of their sex, gender, colour, ethnicity or race (Uromi, 2014). The causes of albinism can be attributed to individuals having "mutations in one of at least 20 genes identified to date" (Moreno-Artero, Morice-Picard, Bremond-Gignac, et al., 2021). Similar, mutation types inherent in both parents

run the risk of bearing children with a similar type. People who have albinism must have inherited one mutated gene from each parent. There is currently no cure for all the types of albinism (Claas, Timmermans & Bruinse, 2010).

Human albinism can occur in isolation or be a symptom of other syndromes, including Chediak-Higashi and Hermansky-Pudlak sub-types, where visual and hypopigmentations exist with other comorbidities. People with Hermansky-Pudlak syndrome (HPS) usually have a type of OCA together with kidney, bowel and lung challenges, bruising and blood disorders (Power, Ferreira, Chen, *et al.*, 2019). Chediak-Higashi syndrome, like HPS, includes a type of OCA, together with neurological and immune disorder and challenges. People with albinism are vulnerable to light and the sun due to their body's inability to adequately produce and process pigmentation (melanin) in their skin, eyes and hair. Many lack colour in the iris of their eyes (Reimer-Kirkmam *et al.*, 2019). These challenges heighten their likelihood of having skin cancer and being visually impaired (Kiprono, Chaula, & Beltraminelli, 2014).

As albinism is a condition experienced by people globally, with estimated statistics of people with varying forms of albinism are one (1) in 17 000 to 20 000 in Europe and North America, with sub-Saharan Africa (SSA) having elevated albinism statistics and Tanzania an estimate prevalence of one in 1 000 (Moreno-Artero, Morice-Picard, Bremond-Gignac, *et al.*, 2021). Parents of children with albinism (CWA) usually ascertain the type of albinism of their child in the first ten years of the child's life and in cases where laboratory diagnostics are available, results may be attained and confirmed through molecular testing (Kromberg, Manga & Kerr, 2020). People with albinism experience disadvantages and challenges as a result of their genetic disorder, including financial and social exclusion, discriminatory practices and acts and psychosocial factors (Marcon & Maia, 2019).

## 2.3 TYPES OF ALBINISM

The primary types of albinism are: Ocular albinism (OA) and Oculocutaneous albinism (OCA).

### 2.3.1 Ocular Albinism (OA)

Ocular Albinism occurs due to a X-linked mutation in the *GPR143* gene and is referred to as *Nettleship-Falls ocular albinism* (Young, Dandekar, Pan, et al., 2016). A contributory factor for OA is an under-developed or incomplete fovea, which is the part of the retina responsible for acute vision, due to shortages or absence of melanin which is required for growth prior to birth (Cancer Association of South Africa (CANSAs), 2021). Hence, people with OA eyes are mostly affected as, “the hypopigmentation is limited to the eyes resulting in irises that are blue to brown, nystagmus, strabismus, foveal hypoplasia, abnormal crossing of the optic fibres and reduced visual acuity” (Grønskov & Brøndum-Nielsen, 2007:5). The severity range for visual impairment can range from acute to chronic and minor to severe (glasses or blind) (Mswela, 2016). Their hair and skin colour are rarely affected, and this type is less common than OCA. It is estimated that 1: 2000 babies are born with OA (Franklin, Lund & Bradbury, et al., 2018). The four types of OA are XLOA, ocular albinism type 1, OA1, Nettleship-Falls ocular albinism and X-linked ocular albinism. A type of OA can be transmitted from a mother to her son.

### Management of OA and Associated Challenges

Some of the challenges associated with OA are sensitivity to glare and various forms of light, Nystagmus which is the involuntary back-and-forth movement of the eyes, Strabismus which is crossed eyes or “lazy” eyes, and visual acuity reduced from 20/60 to 20/400 and even 20/15 in Black Americans (Hertle, 2013). Moving to countries or areas without harsh sun rays or using visual aids (glasses, telescopes, contact lenses) can assist in the management of OA. Eye surgery is an option for PWA with strabismus as it can assist in cases of lazy eyes and self-image. The visual challenges associated

of OA are similar to those of people with OCA.

### **2.3.2 Oculocutaneous Albinism (OCA)**

This is the most common form of human albinism whereby people in this category have pale-coloured skins, hair and eyes. In some instances, where there is no history of familial albinism, in most cases, a baby can be born with the condition due to the PWA having babies with a carrier of albinism. Several sub-types of OCA exist, with the primary four (4) discussed. OCA type 1 occurs due to “mutations in the tyrosinase gene, *TYR*” with individuals usually having light coloured or white hair, lightly coloured irises and pale skin colour and is considered the most severe due to the damage caused by the sun and the impact on vision (Garrison, Yi, & Cohen-Barak, 2004:2; Kromberg, Manga, & Kerr, 2020).

OCA type 1 has not been identified in South Africa, however, a case in Cameroon has been reported. Type 2 OCA is the most prevalent and manifests due to mutations in the *OCA2* gene, previously known as the P gene; in a less severe manner with more diversity as individuals may have blond, light brown or yellow hair and creamy coloured skin tone. Changes in their eyes, hair, and skin colouring may occur later in their lives. This type has three sub-types (*OCA2AE*, *OCA2A*, *OCAB*) and is common in Africa. An estimated prevalence is “... 1:36 000 *OCA2* in the USA but is about 1:10 000 among African Americans” while in certain countries in southern Africa the estimated prevalence is 1: 3 900 (Grønskov, Ek, & Brondum-Nielsen, 2007:2; Kromberg, Manga & Kerr, 2020).

Type 3 OCA is often referred to as rufous oculocutaneous albinism and is prevalent among dark-skinned individuals. It is a milder form of OCA with individuals having this type displaying brown or hazel irises, red or ginger coloured hair and reddish-brown skin hues. Type 3 is rarer than *OCA2* in southern Africa (Manga et al., 2013). Individuals with Type 4 OCA display similar symptoms and characteristics to individuals with Type 2 (Kromberg, Manga & Kerr, 2020).

**Table 2-1: OCA Statistics for South Africa and it’s neighbouring countries**

COUNTRY	RATE	SIZE OF POPULATION SUBGROUP STUDIED	REFERENCE
Botswana	1 in 1 307	18 300 (Isolated village)	Kromberg, 1985 <sup>[9]</sup>
Namibia	1 in 1 755	2 113 077 (Census population)	Lund and Roberts, 2018 <sup>[10]</sup>
South Africa	1 in 3 900	803 511 (Soweto)	Kromberg and Jenkins, 1982 <sup>[5]</sup>
Swaziland	1 in 1 951	160 000 (Hhohho district)	Kromberg, 1985 <sup>[9]</sup>
Zimbabwe	1 in 4 720	1 312 032 (School children)	Lund and Roberts, 2018 <sup>[10]</sup>

**Source:** (Kromberg, Manga & Kerr, 2020)

Statistics retrieved from Tanzania’s 2012 demographic survey estimated that 16 127 PWA lived in the country (Tanzania Government, 2014) while the 2013 Namibian disability survey reflected an amount of 1153 people with albinism living in the country (Namibia Statistics Agency, 2016).

Of concern are the statistics for people with albinism, as most humanitarian organisations and literature cite statistics that were quoted almost four decades ago, yet birth and death rate have increased 40 years later (Kromberg, Manga & Kerr, 2020). Current studies highlight increases in people with albinism, yet the statistics do not reflect these increases. One such example is: Marcon and Maia’s article was published in 2019 yet they quote statistics from Lund (2005); Ben-David (2013;91) and Bologna, Jorizzo, and Schaffer (2012). Another example is the article by Kromberg, Manga and Kerr (2020) who provided statistics from Kromberg (1985) and Kromberg and Jenkins (1982). Statistics of people with albinism in South Africa over the past five years 2016 to 2020 are silent. A critical interrogation with social workers and some officials revealed that few surveys and prevalence rates have been conducted on this vulnerable population, hence their illiteracy regarding statistics of a vulnerable

population that they serve. They cited some reasons for the lack of updated statistics as due to many people with albinism being hidden, murdered or poor statistical records being kept.

## **Management of OCA and Associated Challenges**

- **Visual acuity**

Multi and bifocal glass can assist people with albinism with visual challenges - the use of photocromic lenses and dark glasses which adjust to the light can assist in instances of photophobia while corrective eye surgery and contact lenses can assist Nystagmus (Hertle, 2013; Zungu & Mashige, 2019). In cases of strabismus, some children with albinism have an eye patch on one eye, thereby compelling the non-preferred eye to work. In addition, children with visual challenges sit nearer the chalkboard, have larger font visual material, specialised visual enlargement apparatus or computers which allow for the enlarging of visual material.

- **Skin**

Individuals with OCA may experience sunburn as they do not tan well. Wearing light and thin material items can expose people with albinism to sunburn and the penetration of ultraviolet rays. This can cause skin cancer (Lekalakala et al., 2015). In response to these challenges some people with albinism use sun protection creams with a minimum factor of 15 and clothing that protects them against the harsh sun rays, whether their clothes are dry or wet. However, economic challenges pose a challenge for people with albinism as many cannot afford to purchase it and it is scarce in public healthcare systems (Schühle, 2013). Specialised sunglasses, hats and petroleum jellies are also sources of protection for people with albinism.

## **2.4 LIFE EXPECTANCY AND THE MORTALITY RATE OF PWA**

The morbidity of people with albinism is reported as being within normal limits, as having insufficient or no melanin does not constitute systemic challenges. However, illnesses associated with albinism can result in mortalities due to skin cancer and morbidities such as hearing and visual impairments, blood clotting, skin

photosensitivity (Mabula et al., 2012). In addition, the abuse and murder of PWA can shorten their life expectancy (Tambala-Kaliati, Adomako, & Frimpong-Manso, 2021).

## **2.5 CONSTRUCTION OF ALBINISM**

The construction of albinism and people with albinism is to a great extent based on the difference in hair and skin colour and pigmentation, visual and eyesight challenges and sensitivity to the rays of the sun and light (Olagunju, 2019). Due to these unique characteristics, people with albinism's physical and biological differences result in many behaving and reacting in a manner that people may perceive as indifferent or strange (Bradbury-Jones et al., 2018). Some examples of this behaviour includes wearing hats to protect their skin, wearing dark glasses, squinting, walking accompanied and walking around during the day (Lund & Taylor, 2008; Zungu & Mashige, 2019).

Within the South African context, the country has a history of division, discrimination, racism and apartheid which had hair and skin colour as divisive characteristics (Mswela, 2013; Mswela, 2017). In the context of people with albinism, most are Black but due to their lighter skin colour they might experience discrimination (Mswela & Nöthling-Slabbert, 2013). Within the context of people with albinism, hair and skin colour are predominant characteristics which signal a difference, and this difference can threaten some, thus contributing a large extent to the discrimination, abuse and murder of this vulnerable population (Adediran, 2015; Mswela, 2018). In contrast, this difference can present an opportunity for witchcraft, financial gain through the sale of their body parts and human trafficking.

### **2.5.1 Albinism as a Disability**

In South Africa (SA), albinism being classified as a disability is controversial as clear demarcations and guidelines on what does and does not constitute a disability are unavailable due to limited analytical enquiry being conducted on disability and albinism. However, cases including the *Sutton v United Airlines* in the United States of America

(USA) have previously addressed this conundrum. While the USA has revised their definition of disability to be more inclusive by recognising the human and social rights, human dignity, equality and respect of individuals and the consequences of negative stereotyping experienced by people with albinism, disability in SA is still narrowly defined. According to Myamba et al. (2015), disability includes being mentally and physically disabled or having sensory and intellectual impairments and that disabled individuals do experience discrimination, stigma, and social isolation.

The controversy surrounding albinism and disability is highlighted in the South African Human Rights commissioner's response to the United Nations High Commissioner for Human Rights in Geneva when asked about the status of people with albinism in the country:

*In South Africa, persons with albinism are considered as persons with disabilities. In many communities within South Africa, disability is still generally seen as an illness, shame or curse despite the fact that both Section 9 of the Constitution, Act No. 108 of 1996 and the Promotion of Equality and Prevention of Unfair Discrimination Act, No. 4 of 2000, prohibit unfair discrimination on the basis of disability (SAHRC, 2015; Mswela, 2018:2).*

The limitations and ambiguity of the South African definition of disability has far reaching consequences as the Employment Equity Act 55 of 1998 stated that disability is not extended to individuals who are able to perform the required functions of their assigned jobs, except in cases where their condition cannot be controlled, lessened or checked. In essence, if their albinism is under control, they are not protected from discrimination. Moreover, due to the ambiguity surrounding albinism and the lack of a solid definition of disability in SA, a case instituted by IMATU (IMATU v City of Cape Town, 2005) had to rely heavily on the *Sutton v United Airlines* case. A counter-argument against albinism being categorised and classified as a disability lodged in 2015 by the Acting Assistant Labour Commissioner of Swaziland, Stukie Motsa, a people with albinism, is as follows:

*I personally think it is wrong for people with albinism to be classified as people with disabilities because they are not. They are just normal people and should be treated this way. They are just ill-placed in this category (Ntiwane, 2015; Mswele, 2018: 2-3).*

Moreover, the World Health Organisation (WHO) (2011) and the United Nations (2018) highlighted that disabled people are put at great risk due to community and cultural traditions and beliefs. Disability is considered a socially-constructed challenge, and any societal constructions by society need to be abolished to facilitate people with disabilities enjoying their human rights (United Nations, 2018). Hence, social and human rights travesties, including discrimination due to albinism, should be addressed to ensure people with albinism are equal to others in their country (United Nations, 2015). This is also in line with the Sustainable Development Goals (SDGs):

SDG 3: *Good health and well-being*

SDG 10: *Reduced inequalities*

SDG 16: *Peace, justice, and strong institutions* (UN, 2018).

### **2.5.2 Albinism as a Health Challenge**

Due to people with albinism being sensitive to sun and ultra-violet rays they are susceptible to skin cancer and some die from it around the ages of 30 to 40 years (UN, 2021). However, skin cancer is a preventable and manageable disease should people with albinism apply correct sunscreen, wear sun-protective clothing and regularly attend their medical appointments. In certain countries, people with albinism cannot access health facilities easily nor get the necessary medication and creams they require, resulting in some experiencing health exclusion. Health exclusion is in contradiction to the Sustainable Development Goals which seek to ensure no one is left behind as everyone should experience freedom and inclusion.

## **2.6 RIGHTS OF PEOPLE WITH ALBINISM**

The reviewed literature has revealed various declarations and protocols that ensure the rights of people with albinism. These are discussed as follows:

### **2.6.1 Universal Declaration of Human Rights (1948)**

The Universal Declaration of Human Rights (UDHR) declares all members of the global community have their inherent right to dignity, equality and the inalienable rights as the basis for peace, freedom and justice globally (Universal Declaration of Human Rights, 1948). Furthermore, everyone irrespective of their race, colour, sex, language, religion, health, political or other opinion, national or social origin, property, birth or other status, is entitled to the rights and freedoms of the Declaration. In addition, no distinction on the basis of the political, jurisdictional or international status of the country or territory to which a person belongs, whether it be independent, trust, non-self-governing or under any other limitation of sovereignty is permissible. Thus, all people and nations should be exposed to awareness to understand, protect and promote these rights and freedoms (Universal Declaration of Human Rights, 1948).

The Declaration of Human Rights also categorically states that slavery is prohibited in all forms as all human beings are equal and have freedom of movement and residence within their countries borders (Universal Declaration of Human Rights, 1948). Citizens of their countries have the right to leave and return to their country (Universal Declaration of Human Rights, 1948). The Universal Declaration of Human Rights (1948:33) affords everyone the right to freedom and security of the person, including the right:

- Not to be deprived of freedom arbitrarily or without just cause;
- Not to be detained without trial;
- To be free from all forms of violence from either public or private sources;
- Not to be tortured in any way; and
- Not to be treated or punished in a cruel, inhuman or degrading way.

Another aspect of the UDHR (1948) is its stance that no human being should be subjected to any form of cruelty or torture, discrimination, inhumane or degrading treatment or punishment. In the context of this study, which focusses on the abuse and brutal killing of people with albinism, the UDHR protects everyone, including people with albinism. Hence, the individuals involved in these atrocities are in contravention of this global declaration as all global citizens should be protected, respected and treated with dignity. Moreover, it is inhumane to harvest living people with albinism's body parts for cultural, personal and economic gain. As a global declaration for all, everyone has the right to be protected against such inhumane acts, abuse or attacks. In essence, people with albinism are protected by the declaration. However, statistics, news reports and studies reveal the contrary.

### **2.6.2 Human Rights**

Protecting and promoting the human rights of persons with disabilities is fundamental in all the Articles of the UNCRPD. Notably, Article 4 commits to the full realisation of all human rights and fundamental freedoms for people with disabilities free of all forms of discrimination and to protect all persons against the violation of their human rights. The Bill of Rights, firmly entrenched in the Constitution of the Republic of South Africa (1996), is based on the respect for, promotion, protection and fulfilment of all human rights and justifies the socio-economic rights of all. The Constitution unites the countries three arms (Government, Legislature and Judiciary) to fulfilment of its citizens' rights as their mandates are embodied in the Constitution (Government Gazette, 2016:44).

The Constitution promotes the respect, protection, promotion and fulfilment of the rights of the Bill of Rights and the country's primary responsibility is to guarantee that every individual exercises these rights. In this regard, Section 9 of the Constitution, as entrenched in the Bill of Rights, guarantees the right to equality for all, and prohibits discrimination on the grounds of, among others, disability (Government Gazette, 2016:44). Additionally, the Bill of Rights set out the rights of citizens and the obligations of the State to take reasonable legislative and other measures within its available

resources to achieve the progressive realisation of each of these rights. In terms of education, the Bill of Rights states that "equity, practicability and the need to redress the results of past discriminatory laws and practices" should be achieved (Government Gazette, 2016:44).

### **2.6.3 The Right to Human Dignity**

The Universal Declaration of Human Rights (1948) affirms the right to life, liberty and security of global citizens and rejects torture, cruelty, brutal punishment and any inhumane or degrading treatment. In relation to people with albinism, they, like other people, have the right to enjoy human dignity. In addition, the United Nations General Assembly Security Council (2013) articulated that countries impose steps and take legal action against the perpetrators of abuse, attacks, harvesting and murder of people with albinism.

The assembly condemned such attacks and stressed the importance of providing shelter to people with albinism under threat, attack, and also to heighten public awareness through campaigns. Additionally, the United Nations General Assembly Security Council (2013) urged countries to implement necessary measures to ensure the safety, protection and investigation of people with albinism and their family members. Furthermore, the United Nations General Assembly Security Council (2013) stressed that effective measures be implemented to eliminate all types of discrimination against people with albinism by increasing and accelerating education and public awareness programmes. Countries should share best practices that protect and promote the safety, protection and the rights of people with albinism. There is a need for collaboration between regional, national and international organisations, one that promotes bilateral, regional and international initiatives to support the protection of persons with albinism. Finally, the United Nations General Assembly Security Council (2013) encouraged the Office of the United Nations High Commissioner of Human Rights to submit reports on attacks and discrimination against PWA to the Human Rights Council to ensure that such practices are discontinued and the perpetrators punished.

## **2.6.4 The Right to Social Security**

Citizens should have the right to social security which entails countries must protect all their citizens, either through assistance or social welfare. This includes vulnerable populations and communities, such as people with albinism. This right should protect people with albinism as they are socially included and socially and financially protected in cases of poverty. According to the South African Government Gazette (2016), people with albinism are people like everyone else in society and therefore have rights like everyone else. The document stated that albinism be treated as a disability and that people with albinism have the same equal rights as people with disabilities.

## **2.6.5 Political Rights**

According to the South African Government Gazette (2016), persons with disabilities have political rights and every endeavour must be made to create opportunities for them to exercise this right - their political rights - by being able to vote and/or be elected to serve in public office. This means that people with albinism can and should be involved in voting processes and procedures and have access to facilities and materials which is achievable through advocating for their rights and the development and increase of public awareness thereon (Government Gazette, 2016:44).

## **2.6.6 Social Rights**

In endeavours to ensure people with disabilities have equitable social rights, they must enjoy the right to education, healthcare, housing, transport, sport, recreation, culture, social development services, food security and family life. However, there is a need to build socially-cohesive communities, improve education and health and build safer communities. This can be achieved through the application of a social model, a mainstream approach, social rights, and the development and empowerment of children, youth and women with disabilities within all the NDP outcomes (Government Gazette, 2016:47).

Critical to building social cohesion is enabling persons with disabilities to live in barrier-free environments within their communities. Social cohesion should also provide individuals requiring support with the means to participate in community life, and expanding ECD programmes, with government support, to reach all vulnerable children, including children with disabilities. It is imperative that the social rights of people with disabilities promote accelerated the roll-out of inclusive education which will enable everyone to participate effectively in a free society. It also acknowledges that education provides knowledge and skills that persons with disabilities can use to exercise a range of human rights, such as the rights to political participation, work, live independently, contribute to the community, participate in cultural life, and to raise a family (Government Gazette, 2016:47).

Equally important is the role the NDP sees for the post-school sector as it relates to the promotion and realisation of the rights of persons with disabilities as citizens with equal rights. There are nine health-related goals that are relevant to improving the lives of persons with disabilities aimed at transforming the healthcare system by removing attitudinal, physical, communication and information barriers, skilling health personnel to provide equitable services to persons with disabilities, reducing the cost of medical care and strengthening access to disability-specific health services, which will enable persons with disabilities to live longer, be healthier, live with dignity, and contribute better to the development of their communities and the economy (Government Gazette, 2016:47).

Chapter 12 of the NDP on Building Safer Communities provides for specific measures to be taken which are to ensure that all vulnerable groups, including women with disabilities, enjoy equal protection and that their fear of crime should be eradicated through effective, coordinated responses by the police, business, the community and civil society. It also focuses on strengthening the judicial system to be more effective, efficient and accessible (Government Gazette, 2016:47).

### **2.6.7 Economic Rights**

Economic rights are the cornerstone of economic programmes, policies and plans hence, all citizens should be able to participate in economic processes equally with dignity. These economic rights facilitate access to the infrastructure, resources including finance, capital and labour. Empowering and promoting citizens' economic rights facilitates their independence to provide for and meet their basic human needs, resulting in them living with dignity and self-respect. Citizens' ability to achieve and maintain economic freedom is the aim of economic justice as people expressing their economic rights facilitates them living a productive, fulfilling, dignified and creative life, which reduces income inequalities and poverty levels (Government Gazette, 2016:49). With regard to economic rights, persons with disabilities actualise the social model and mainstreaming approach as they are able to participate in the conceptualisation, development, implementation and monitoring of economic programmes and policies (Government Gazette, 2016:49). Hence, people with disabilities including people with albinism, must be included in economic development targets and indicators (Government Gazette, 2016:49).

### **2.6.8 Cultural Rights**

Cultural rights include the participation in cultural production, language, heritage and culture that facilitate individuals enjoying and practising their culture within the ambits of non-discrimination, equality and human dignity (Government Gazette, 2016:48). These rights are weaved into citizens' sense of identity. Hence, cultural challenges to one's cultural rights impinge on an individual's sense of value and integrity and threaten their understanding of their beliefs, world, culture and wellbeing. As a result, challenges to culture generate strong, emotionally-charged, survival responses. Cultural rights are complex and multifaceted as there are inextricable links to power whereby dominant cultures impose their perceptions, thought patterns and beliefs on weaker members of society (Government Gazette, 2016:7). Article 30 of the UNCRPD places specific obligations on the state to take measures that will promote, protect and uphold the cultural rights of all people, including persons with disabilities, and their right to

participate in cultural activities and their cultural heritage (Government Gazette, 2016:7).

### **2.6.9 The Right to Life**

Section 11 of the South African Constitution recognises the right of all citizens to life and was chronicled in the *Carmichele* case that stated that entities and people are obliged to refrain from infringing on citizens right to life. The right to life errs on the protection of all citizens through processes, laws and agencies facilitating and providing such protection (The Constitution of the Republic of South Africa, 1996). In Tanzania, where discrimination against people with albinism is at heightened proportions, the right to life is guaranteed in the Tanzanian Constitution under Article 14 Penal Code of the Republic of Tanzania 1981, (The United Republic of Tanzania National Human Rights, 2017). Any violations of this right in Tanzania warrants the death penalty, thus rendering and entitling all Tanzania citizens to the protection of their lives. Moreover, Article 3 of the Universal Declaration of Human Rights promotes the right to life, liberty and security of citizens (Universal Declaration of Human Rights, 1948).

### **2.6.10 The Right to Equality**

Unfair discrimination is a violation of people's right to equality, as enshrined in the South African Constitution (South African Human Rights Commission, 2017). The right to equality facilitates the equality of South Africans irrespective of their gender, sex, race, religion, political affiliations, opinions, health and disabilities to ensure citizens enjoy their fundamental rights and freedom. Hence, any discrimination of people with albinism is a violation of their right to equality. People with albinism have the same right to freedom, security and human dignity as all South African citizens. Hence all forms of discrimination and their murder violates their rights and the South African Constitution.

### **2.6.11 Mainstreaming a “Rights-based Approach”**

Mainstreaming links participation, accountability, non-discrimination, empowerment to the human rights of citizens. A rights-based approach is aimed at developing programmes that improve citizens’ quality of life. The South Africa Constitution guides the legal framework of participatory democracy in the country by facilitating a rights bank comprising the right to assemble, freedom of expression, freedom of speech, to demonstrate, petition and vote. Examples of participatory democracy are a citizen’s inclusion of workplace forums, ward committees and Integrated Development Planning (IDP) Processes. "Participation is a basic human right in itself, a precondition or catalyst for the realisation and enjoyment of other human rights, and of fundamental importance in empowering people living in poverty to tackle inequalities and asymmetries of power in society" (Government Gazette, 2016:45).

The Preamble to the Constitution positions the South Africa government as squarely situated to ensure social justice and its citizens a quality of life through the principles and values of “*human dignity, the achievement of equality and the advancement of human rights and freedoms*” (Government Gazette, 2016:45).

## **2.7 TYPES OF ABUSE LEVELLED AGAINST PEOPLE WITH ALBINISM**

Globally, with Africa and South Africa being no exception, people with albinism have lived with and experienced persecution, various types of abuse, discrimination, social exclusion, bullying, negative labelling, murder and the harvesting and sale of their body parts on the black market (Larson, 2011; Mswela, 2013; Benyah, 2017; Mswela, 2017). However, in as much as the abuse and killing of people with albinism is a global issue, a study by Maia et al. (2015) highlighted that this situation is not as prominent in Brazil. While incidents of abuse and violence against people with albinism living in SSA has received great media attention, with several media outlets reporting on them, such incidents are not limited to urban areas but include rural areas as well (Maia et al., 2015; Kromberg, 2018; Under the Same Sun, 2018). Just over the past decade, the abuse

and killing of people with albinism on the African continent has received heightened exposure on the continent and internationally (Schühle, 2013).

### **2.7.1 Physical Attacks and Murder**

People with albinism are physically attacked due to the physicality and their body parts. Ritual attacks have contributed to many African people with albinism being maimed or murdered. Children with albinism are easy human targets of physical attacks and infanticide due to their physique and vulnerability. They are attacked due their innocence and younger body parts which are “suitable ingredients” for potent potions (Under the sun, 2012). The brutal maiming and murder of people with albinism across Africa is well-documented, with many being traced and tracked down by opportunistic individuals who eke out their living from the sale of people with albinism body parts as they attract premium rates on the black market (Cruz-Inigo, Ladizinski & Sethi, 2011). Such attacks have been identified in 28 countries across Africa (Open Society Foundations, 2019).

### **2.7.2 Exclusion**

#### **2.7.2.1 Employment Exclusion**

Gainful employment of all human beings is core to their existence, yet people with albinism find their condition a challenge as some employers exclude people with albinism due to perceptions that they are cumbersome, a management challenge and incapable of working in permanent positions. Employers and fellow employees can be insensitive by assigning them to work in the sun without considering their sensitivity to the sun and its harsh rays. In addition, Lekalakala et al. (2015) highlighted the dangers of skin cancer on the people with albinism which can result in them being absent from their workplaces due to them attending hospital or doctors for monitoring, care and treatment. Moreover, their visual impairment or loss of limbs or body parts could limit the types of employment they could pursue (Fourie, 2020). Their physical (loss of

limbs, visual impairment) and health (skin cancer) challenges and slower work performance due to these challenges, coupled with them being prevented from attending school and tertiary institutions by family members or caregivers, renders them unequal in the labour market (Fourie, 2020).

### **2.7.2.2 Educational Exclusion**

Many educational institutions are not cognisant of people with albinism's challenges regarding their visual capacity and in some cases assign them to learning environments with harsh lighting, the use of coloured writings, provide them with prescribed readings, textbooks and other learning material with small fonts and font sizes that are not conducive to their visual challenges (Uromi, 2014). In addition, many parents or caregivers choose not to send their children to school out of fear of them being discriminated against, abused or murdered or trafficked for their body parts. This means that parents with children with albinism are very protective to their children from the public who abuse their children (Franklin et al., 2018).

On the one hand the child is being excluded from having an education and educating him/herself to be independent and triumph over any poverty circumstances. While on the other hand, the child could be protected and live to be older. However, being excluded because of the fear of being abused and murdered is stressful as one cannot enjoy the liberty of being free to socialise as one is constantly aware of being a scarce, much required commodity due to other people's greed and ignorance. Being uneducated and maybe unable to communicate on par with others your age can contribute to a poor or low self-esteem, being antisocial and limiting the chances of being gainfully employed (Benyah, 2017).

### **2.7.2.3 Familial Exclusion and Marital Challenges**

Persons with albinism are psychologically and socially isolated and excluded due to familial and social exclusion resulting from the behaviour and attitudes of family and community members. In Tanzania, women experience discrimination, abuse and

exclusion when they give birth to a child with albinism. They are rejected by their husbands and their families as well. These women are viewed as bringing bad luck and disgrace to the families due to the myths that children with albinism are conceived through sexual promiscuity with men of other races or men who are cursed and unclean. They are also accused of being witches. Moreover, children with albinism are hidden and forbidden to be seen in public or even killed due to them being perceived as a disgrace to the family (Benyah, 2017). Such exclusion is not only evident within the family but spills into the educational and employment limitations of people with albinism as parents keep them homebound, do not send them to school or university thereby limiting their educational and employment opportunities. People with albinism also experience challenges when seeking life or marital partners due to the self and public stigma attached to having albinism and many feel compelled to live single lives or one of solitude and exclusion (Benyah, 2017). Additionally, a person with albinism is not encouraged to marry a person without albinism as a means of curbing the spread of albinism.

### **2.7.3 Abandonment**

Some children born with albinism are abandoned or surrendered with confidence to their families, relatives and strangers to raise (Mogale, 2018).

### **2.7.4 Labelling**

Across Africa, people with albinism experience stigma and exclusion through labelling. And are addressed by discriminatory and offensive labels and names due to their physical appearances resulting in stereotypes being assigned to them (Brocco, 2015; Murray, 2015). In the Democratic Republic of Congo, people with albinism are referred to as “*mbunzu gozo*” which means “*black eater of manioc*” in the Sangho language. This label reflects people’s perceptions of the condition and the ambiguous defining and beliefs attached to disability as people with albinism are considered disabled (Ogrizek, 1983, 28). In Malawi, people with albinism are referred to as “mzungu”,

meaning a European or white man and “napwere” in reference to a “pea-brownish colour” (Braathen & Ingstad, 2006: 606). Similarly, in Mali, people with albinism are referred to as “gomblè” meaning a “red man” due to them being sunburnt resulting in their skin being red due to the sun (Imperato & Imperato, 2006). Also, the labels “Zeru” meaning “ghost like creature”, “mzungu” meaning “white man”, “shawa” meaning “monkey” are assigned to people with albinism in east and southern Africa including Zimbabwe, Tanzania, South Africa, Malawi and Mozambique. Discriminatory labelling demonstrates a power dynamic as perpetrators of labelling believe the balance of power is skewed in their favour, hence they levy labels at people they marginalise, such as people with albinism (Singal 2010; Ginsburg & Rapp, 2013). Women with “albinism and those giving birth to children with albinism are labelled “witches.

### **2.7.5 Financial Challenges and Exclusion**

Due to the impact of the sun and ultra-violet (UV) rays, people with albinism require special sunscreen, petroleum jellies, hats and specialised sunglasses which come at a cost which many cannot avoid to purchase or access. Inadequate medical attention to treat the condition predisposes them to the risk of skin cancer (Pillay, 2013).

## **2.8 FACTORS CONTRIBUTING TO THE ABUSE AND KILLING OF PEOPLE WITH ALBINISM**

### **2.8.1 Patriarchy, Culture and Tradition**

The patriarchal nature of many countries renders women as subordinates in their families, workplaces and communities, thereby facilitating, to some extent, females with albinism vulnerable to abuse. Societal and communal myths also contribute to the abuse and killing of people with albinism as the birth of a child with albinism is perceived as the mother having sexual intercourse with unclean and cursed men and men of other ethnicities and races (Cruz-Inigo, Ladizinski & Sethi, 2011). These age-old myths are still prevalent and practised world-wide (Open Society Foundations, 2019; United Nations, 2020). Killings have been reported in Kenya, Uganda, Congo and Burundi in

efforts to sell the organs in Tanzania (Allen, 2010). The trend has now hit southern African countries with killings reported in Swaziland and Zimbabwe. Similar cases have been reported in Mali, West Africa. Also, people in Benin believe that the blood of people with albinism has magical properties and that it brings prosperity and luck. The fingers of people with albinism are worn on necklaces around people's necks as lucky charms ([www.albinism.org.uk](http://www.albinism.org.uk)). Open Society Foundations (2019), Lund and Gaigher (2002) reported that these killings are associated with a belief that people with albinism's blood has supernatural powers that brings prosperity and good luck.

The situation is worse in Central Africa where people with albinism are regarded as sacrificial lambs. The demand for people with albinism body parts has resulted in callous attacks levelled at them ([www.albinismfoundationea.com](http://www.albinismfoundationea.com)). The murder of babies with albinism at birth have been observed in some communities as it is perceived that they do not live long hence their lives need to be cut short, which is against their constitutional right to life (Allen, 2010, [www.albinism.org.uk](http://www.albinism.org.uk)). In addition, there is a prevailing myth in South Africa regarding people with albinism death in that they do not die a natural death but vanish in the bush (Lund & Gaigher, 2002).

### **2.8.2 Discrimination and Stigma Based on Appearance, Difference and Uniqueness**

Globally, most people with albinism experience several forms of stigma and discrimination due to their condition, physical appearance and misleading myths and belief systems that are fuelled by superstition (United Nations, 2020). Within the African context the physical appearance of Black African people with albinism in comparison to other Black Africans is stark as they have a paler skin colouring than the majority of Africans (Aceves, 2015). This stark difference is subject to varying interpretations, with some viewing this as ghost-like, a curse while others view them as holding mystical, magical or supernatural powers (Mártinez-García & Montoliu, 2013). Furthermore, although most people with albinism living in Africa are Black, their lighter coloured skin does not preclude them from being discriminated against based on racial identification (Fourie, 2020).

These perceptions that people have of them contribute to their vulnerability to be abused or murdered as they are viewed as marked targets, suspicious, mysterious, abnormal and evil due to their physical appearance. Such perceptions impact their self-esteem and how others view them (Gifford, 2015). Various forms of stigma and discrimination are experienced by people with albinism, such as self-stigma which arises when people with albinism stigmatises themselves due to their physical appearance or condition. Additionally, public stigma occurs and is external as other people label, discriminate or stigmatise people with albinism based on their condition or appearance.

### **2.8.3 Finances**

Across Africa, people with albinism, including women, children, men and the aged, are hunted for their body parts (hair, limbs and heads) as the sale of these body parts is a lucrative business (Cruz-Inigo, Ladizinski & Sethi, 2011). The harvesting of people with albinism body parts featured prominently in Tanzania a decade ago. However, the tragic, murderous harvesting of human body parts has also been reported in Mozambique and Malawi and subsequently across Africa (Open Society Foundations, 2019). Contrarily, China, France and South Africa have also reported on this human rights travesty (Brilliant, 2015; United Nations General Assembly, 2015).

In Tanzania, body parts from people with albinism sell for approximately \$600 with complete bodies securing \$75,000 (UN, 2014), while, a South African woman was arrested for allegedly attempting to sell a 12-year-old boy with albinism to a traditional healer for R100 000 in Manguzi in KwaZulu-Natal (Mabona, 2018:2). Seasons play a role in these atrocities as around governmental elections an increase in the murder of people with albinism occurs as some people believe that their bodies carry mystical, magical and supernatural powers. They deem that these magical powers can positively sway elections or re-elections so that specific politicians can be brought into power (Mtetwa, 2010; United Nations, 2020). Some individuals perceive these organs as sources of luck aimed at the enrichment of their lives and well-being (Mswela, 2017).

Moreover, murders, appear to be driven by traditional “witchdoctors” who provide contract killers with their requirements aimed at meeting the demands for the body parts of PWA as certain body parts bring wealth and fortune. The killing of people with albinism and the harvesting of their body parts is a booming business, resulting in graves being dug up and body parts being harvested for traditional witchdoctors to make charms as magical potions (Pillay, 2013; United Nations, 2020).

#### **2.8.4 Witchcraft and Murder in Africa**

Witchcraft has no universal definition and represents and means different things for different people. Many associate witchcraft with negativity, wickedness and witches who practise evil with negative consequences (Foxcroft, 2018). In many African countries, harmful witchcraft-related beliefs and practices contribute to human rights violations, including physical beatings, banishment, torture, mutilation and amputation of body part mutilations and murder. Women, children, the elderly and persons with disabilities and people with albinism, are particularly vulnerable to witchcraft practices and their consequences (Foxcroft, 2018). Precise statistics of victims of witchcraft are silent. even though the practice is well known. The killing of people with albinism is also associated with water spirits that protect polygamous men and restore their dignity and place in the household and earns them respect in their family with women holding them in high esteem. As such, women in polygamous marriages who do not fight are always in good relationships. It is believed that the spirit of a people with albinism chases away all other confusing spirits that result in toxic families or marital problems (Machoko, 2013). Others murder people with albinism as they believe their murder can facilitate promotions in their workplace.

There is a strong belief driven that the body parts of a people with albinism possesses magical powers capable of bringing riches (Makulilo, 2011; Fourie, 2020). According to NOAH (2005), traditional healers, diviners, and herbalists are the main perpetrators of abuse of people with albinism as they believe that the parts are good to create charms. In countries such as Tanzania, South Africa, Zimbabwe, to mention a few, there is a

widespread practice of mixing charms with people with albinism body parts, especially the hair, breasts, fingers, tongue, genitals, limbs and blood to create strong magical fortune (NOAH, 2005; Foxcroft, 2018). In African communities, the strong belief that the body parts of people with albinism have supernatural power, has increased in eastern Africa and Southern Africa over time and contributes to expectations of a great deal of fortune by body part traffickers. Traditional beliefs and inclination by the authority of local healers (witch doctors) in explaining sources of hardships or misfortunes fortify the vulnerability of people with albinism.

In many rural areas in Africa, people with albinism are severely attacked because of the growing traditional beliefs of fortune associated with people with albinism body parts. Traditional African beliefs and cultural attitudes about them and their families further contribute to their social exclusion. People with albinism being kidnapped and murdered for portions of good fortune, witchcraft, magic are prevalent in East Africa and other parts of Africa. In Mozambique, Malawi, Botswana, Swaziland, Tanzania and South Africa, people with albinism body parts are used for medicine to cure various illnesses (Makulilo, 2011; Foxcroft, 2018). Moreover, in areas where people with albinism live, it is still believed that they yield magical powers that can facilitate forms of prosperity or success (Fourie, 2020).

In countries such as Tanzania, South Africa and Zambia, more than 100 people with albinism have been murdered and their body parts used by witchdoctors and traditional healers to bewitch polygamous wives to love their husbands (Salewi, 2011). Moreover, the murder of people with albinism is conducted to use their body parts for the manufacture of charms for traditional witchdoctors. Witches also indulge in the illegal trade of the skin, hair and bones of people with albinism to be used as potions and charms to bring people good fortune and enrich them. As previously mentioned, people with albinism graves are dug up and pillaged for body parts for witchcraft purposes (Maluleka & Nkwe, 2022).

The majority of reported murders have taken place in the northern Lake Region in Tanzania, although there have also been reports of murders in countries sharing its

borders. These murders have taken place in remote regions where the inhabitants are rooted in traditional beliefs and more inclined to comply with the authorities of witchdoctors in enlightening the causes of their hardships or misfortunes. Witch doctors who reside in these villages are revered and respected. Such fear has led some villagers to kill a family member purely because a witch doctor has instructed such a murder. A recent case, reported in July 2011 in South Africa, referred to an albino boy who went missing on his way home from school and was believed to have been snatched with the intent of using the child for the purpose of a tribal sacrifice (Foxcroft, 2018; Maluleka & Nkwe, 2022).

The recent disappearance of the 14-year-old albino adolescent, Sibisuso Nhatave, led to an extensive investigation in the eastern province of KwaZulu-Natal, as he was feared to have been a victim of witchcraft and murder for his body parts. Another recorded scandalous case in South Africa associated with albinism and concoction (*muti*) was that of Sipho Lolwane, an albino who passed on in 2002 and whose grave was defiled and robbed a number of times for the remains of his bones. Police spokesperson, Captain Amanda Funani, stated that a diviner (*iSangoma*) and his driver had been apprehended with the bones of Sipho Lolwane, discovered by the police while patrolling the Moletsamongwe cemetery in Modimola. The police guarding the area noticed the diviner (*iSangoma*) and his driver departing from the cemetery with a bag.

The killing of people with albinism in East and Southern Africa, especially in South Africa, Malawi and Tanzania, have woken the world up to the threats facing people with the condition. Reports from various sources indicate that about 100 persons with albinism may have been killed in South Africa, Tanzania and Burundi in the past few years. The killings are done in order to harvest body parts which are used in the making of charms by traditional witchdoctors. It is believed that charms made with body parts of persons with albinism, especially hair, genitals, limbs, breasts, fingers, the tongue and blood make strong magic portions which fetch higher prices. In Tanzania, organs can go for a high price. For example, a leg or an arm can fetch between US\$1,000 and US\$3,000 - big money in a country in which the annual average income is just \$800. The killings

are known to peak during election times as the demand increases for magical portions by politicians seeking election or re-election. Killings have been reported in Kenya, Uganda, Congo and Burundi, possibly to sell the organs in Tanzania. The trend has now hit Southern African countries, with killings reported in Swaziland and Zimbabwe. Similar cases have been reported in Mali, West Africa. Also, people in Benin believe that the blood of persons with albinism has magical properties and that it brings prosperity and luck. The fingers of persons with albinism are worn on necklaces around people's necks as amulets (Uromi, 2014).

## **2.9 THE COPING STRATEGIES OF PEOPLE AFFECTED BY THE ABUSE AND KILLING OF PEOPLE WITH ALBINISM**

Instances, observations and experiences of the abuse and killing of people with albinism negatively impacts this vulnerable population as they feel traumatised, and constantly have to be vigilant by always looking over their shoulders, taking flight from their homes and places of employment and becoming reclusive and anti-social in endeavours to avoid violence and losing their lives. Abuse, discrimination and murder are sad realities confronting people with albinism, with the primary drivers of this human atrocities being superstition, myths, ignorance, a lack of correct information and awareness. Worth noting is that the biomedical and humanitarian perspectives are prefaced at the expense of the social players (people with albinism) - lived experiences are put on the back burner with most research being conducted on the former and research relating to people with albinism lagging behind. A study that addressed the psychosocial challenges and coping strategies of people with albinism was conducted in Tanzania found that they lived under threat due to the way they are treated. However, the efforts of non-governmental, non-profit and community-based organisations (CBOs) cannot be ignored as they play a pivotal role in highlighting the plight of people with albinism and the transgression of their rights.

The abuse and killing of people with albinism has catastrophic consequences which necessitate a multi-disciplinary coping approach. The health of people with albinism is

paramount to them due to their excessive sweating, being predisposed to sunburns and skin cancer, hence they have to attend skin care facilities and hospitals for regular check-ups, treatments and medication (Esther, Hajo & Michael, 2006). Their psychological and mental health also requires attention, hence some people with albinism utilise the services of social workers, psychologists and therapist to seek assistance. Limited literature exists on their coping strategies; thus this study will fill that literature gap.

## **2.9 INTERVENTION STRATEGIES AIMED AT PREVENTING THE ABUSE AND KILLING OF PEOPLE WITH ALBINISM**

### **2.9.1 International Albinism Awareness Day**

The brutal attacks on, and murders of, people with albinism in the mid-2000s resulted in rigorous lobbying for people with albinism rights, which resulted in resolution 26/10 of June 26, 2014, on albinism being passed as a result of the Human Rights Council's intervention. As a result, on 18 December 2014, the UN's General Assembly adopted that the 13<sup>th</sup> of June each year would be proclaimed as International Albinism Awareness Day. Themes for subsequent years are below:

**Table 2-2: International Albinism Awareness Day Themes**

Year	Theme	Message
2016	Celebrate diversity; promote inclusion; protect our rights ( <i>The Guardian, 2016</i> )	This theme is about celebrating people's differences resulting in people with albinism being included and their rights being protected
2017	Advancing with renewed hope ( <i>Albinism in Africa, 2017</i> )	This theme focussed on providing renewed hope for people with albinism to persevere, despite the fear and opposition they face daily. to bring awareness to albinism and realise an educated vulnerable group of people.
2018	Shining our light to the world ( <i>OHCHR, 2018</i> )	The theme focussed on showing that people with albinism have positivity which needs to be shared with the world in the midst of abuse, discrimination and killing.
2019	Still Standing Strong	The theme focussed on the global community recognising, and being in solidarity with people with albinism and celebrating them, and highlighted that despite the challenges they were confronted with, they still remain resilient.
2020	Made To Shine	This theme focussed on celebrating people with albinism successes and achievements and for the global community to stand in solidarity with them through their challenges.
2021	Strength Beyond All Odds	This year's theme elevates the positive qualities they have despite defying numerous life-threatening odds by meeting and exceeding the challenges and expectations of life.

**Source:** (National Organisation for Albinism and Hypopigmentation, 2021)

The abuse and killing of people with albinism is a human, global concern and in

recognition of their challenges and strengths the theme for the International Albinism Awareness Day on 13 June, annually. According to the United Nations (2020), in this unprecedented time of COVID-19, the people living with albinism continue to suffer all types of human rights violations. For example, in some countries they are called names like “Corona” or “COVID-19” in an attempt to scapegoat them for the pandemic. Additionally, killings, attacks, bullying, dehumanising stigma and discrimination continue against people with albinism. Hence, the United Nations (2020) called for the global community to respect people with albinism as they are human beings. The information and literature discussed reveals the need for all global citizens to fight the discrimination and murder of people with albinism and work towards a world free of discrimination, fear, violence and stigma.

Additionally, the abuse and killings of people with albinism had aroused the awareness of people, organisations, community-based and non-governmental organisations about this scourge and resulted in many awareness campaigns and much outreach. An awareness campaign was established on June 13, 2014, as International Albinism Awareness Day by the UN General Assembly. The awareness campaign was meant to educate the society to stand against the discrimination, abuse, and killing of people with albinism (United Nations General Assembly, 2017). International Albinism Awareness Day by the United Nations General Assembly (2015) had to address the following issues:

- The campaign was meant to teach the African Commission on Human and Peoples’ Rights resolution 263 of 5 November 2013 that it was inhuman to attack and discriminate against persons with albinism;
- The campaign was also meant to express concerns regarding the attacks against women with albinism, including their children;
- The campaign was also meant to encourage member states to continue their efforts to protect and preserve the rights of persons with albinism to life, dignity and security, as well as their right not to be subjected to torture and cruelty, inhuman or degrading treatment or punishment, and to continue their efforts to

ensure equal access for persons with albinism to employment, education, justice and the enjoyment of the highest attainable standard of health;

- The campaign emphasised the imperative need to enhance the promotion and protection of all human rights, including economic, social and cultural rights, as a matter of priority for the international community;
- The campaign emphasised the need, in many parts of the world, that awareness of the human rights situation of persons with albinism should remain, and recognising the importance of increasing awareness and understanding of albinism in order to fight against global discrimination and stigma against persons with albinism;
- It emphasised the importance of punishment of people who are the perpetrators of abuse and killing of PWA;
- The campaign announced public awareness campaigns to educate people that it is only through hard work that one can prosper in life, not through the sale or use of body parts of fellow human beings with albinism;
- The campaign ensured that the formation of the multi-disciplinary National Task Force, which would trickle down to the regional and district levels for the purposes of brainstorming, researching and suggesting ways to deal with the problem; and
- To ensure that there is a nationwide campaign intended to identify suspected perpetrators in people with albinism killings.

According to the United Nations (2020), in African countries such as Tanzania, Namibia, South Africa, Swaziland, Mozambique, Kenya, just to mention a few, it was reported that people with albinism are severely discriminated against. The body parts of the people are used for performing rituals. There are hundreds of cases of attacks and the killing of persons with albinism reported in 28 countries in Sub-Saharan Africa (SSA) over the past decade. The attacks were rooted in ignorance, stigma, poverty and harmful practices emanating from witchcraft and cultural beliefs, with these horrendous practices still continuing today.

The United Nations (2020) has continued to highlight the manner in which people with

albinism discrimination manifests and varies from country to country and region to region. In the western world, including North America, Europe and Australia, discrimination often consists of name-calling, persistent teasing and bullying of children with albinism. Little information is available from other regions such as Asia, South America and the Pacific etc. However, some reports indicate that in China and other Asian countries, children with albinism face abandonment and rejection by their families.

Based on the above threats towards people with albinism, the European Parliament (2018) posited that it is the duty of countries to ensure that all their citizens, including people with albinism, are protected to uphold their right to life and security. This is in keeping with international human rights' obligations and commitments. African governments have been mandated to have proactive measures in place against human trafficking and witchcraft advocates and perpetrators of people with albinism. In addition, they need to upskill police officers by providing them with relevant training and equipment to systematically address and apprehend perpetrators of crimes against humanity (European Parliament, 2018). When and where necessary, African countries should seek international assistance to address investigations of crimes against people with albinism to hold perpetrators accountable or bring them to justice.

### **2.9.2 Organisation's Addressing Albinism**

Globally, several organisations provide counselling and assistance to people with albinism. Searches on organisations in the South African context revealed the electronic visibility of the following organisations:

- Albinism Advocacy for South Africa. This is a blog on Facebook developed to create awareness of albinism and the protection of their rights (Cancer Association of South Africa (CANSA), 2021).
- Albinism Society of South Africa

This society is in Soweto and has approximately 200 members.

- Centre for Human Rights – University of Pretoria

This centre is situated within the University of Pretoria and its key focus is on the advancement of human rights, which includes those of people with albinism. This is conducted through awareness, activism, education and research ([www.chr.up.ac.za](http://www.chr.up.ac.za)).

- Human Rights Media Centre

This non-profit centre is based in Cape Town and documents narratives that address activism, education and human rights awareness. Though its core population is people in South Africa who require their services, people with albinism form part of their target population.

- Khulisa Social Solutions (KSS)

This is a non-profit organisation, registered in 1997, whose core focus is in on marginalised and vulnerable individuals living in South Africa, with the aim of assisting them unlock their potential and to live meaningful lives (Khulisa, 2021).

- Kwatsaduza Albinism Society Initiative

This is an organisation that is based in Ekurhurleni with a strong focus on self-representation, active citizenship and an active social media presence (United Nations, 2021).

- Love this skin

This is a non-profit organisation that facilitates people with albinism seeing beyond their physical appearance and motivating them that their being, lives and experiences are relevant and worth hearing and sharing (United Nations, 2021).

- Ibutho Lezwe Foundation

This is a non-profit organisation established in 2017 to draw attention to, and raise awareness of, albinism, aimed at eliminating stigma in all spheres of society (United Nations, 2021).

- Masiqogane Albinism Foundation

According to the Sowetan Newspaper (2020), Masiqogane Albinism Foundation was found by Ngcobo who lives in Durban, South Africa. Ngcobo started the organisation because he personally has suffered from violence and discrimination due to the misconceptions of his condition. The Masiqogane Albinism Foundation is meant to raise awareness of the abuse of people with albinism in the country and abroad. It is a foundation that addresses all problems related to people with albinism.

- The South African Inherited Disorders Association (SAIDA)

This is a support group consisting of 30 members to focus on public awareness and education on albinism. The group falls under the umbrella of the SAIDA (SAIDA, 2021).

### **2.9.3 Legal System and Police**

The South African Constitution and the Bill of Rights enshrined in the Constitution protect all its citizens, including people with albinism. The Integrated National Disability Strategy (1997), Promotion of Equality and Prevention of Unfair Discrimination Act (2000) and the UN Convention on the Rights of Persons with Disabilities (CRPD) all recognise the rights of PWA. Moreover, Article 8 of the CRPD requests countries to implement urgent, relevant and effective measures to raise awareness of people with disabilities, differences and challenges. In 2012, a National Development Plan was commissioned by the South African National Planning to ensure the safety of South African Communities (NPC, 2012). The primary gatekeeper of this plan was a professionally, fully resourced police force, comprising skilled, responsible and

committed police officers and administrators who would service and protect communities within the ambits of respect, equality, and justice (Mabasa & Olutola, 2021). However, despite policies, procedures and a police department being in place to protect the citizens of South Africa, crime is still at epic proportions (Mabasa & Olutola, 2021). This was further indicated by South Africa's 2020-2021 crime statistics for the fourth quarter (Table 3) that were presented by the Police Minister, Bheki Cele. Although no statistics were presented for the murder of people with albinism, the statistics for murder and attempted murder had increased by 8.7% and 8.4% which was very important as this is the subject of this study. The Minister's further concern was the levels of crime in KwaZulu-Natal and the Eastern Cape - and KZN forms the setting for this study. Hence, the collected data has found context in these statistics.

**Table 2-3: Quarter One Crime Statistics 2021/2022**

<b>Category</b>	<b>Jan—Mar 2020</b>	<b>Jan—Mar 2021</b>	<b>Change</b>
Truck hijacking	284	354	+24.6%
Commercial crime	20,193	22,558	+11.7%
Attempted murder	4 216	4 582	+8.7%
Murder	4 589	4 976	+8.4%
Robbery at residential premises	4 916	5 288	+7.6%
Carjacking	4 303	4 513	+4.9%
Robbery at non-residential premises	4 741	4 872	+2.8%
Bank robbery	0	1	+1 case
<i>Sexual offences discovered because of police action</i>	2 377	2 335	-1.8%
Sexual offences	12,627	12,133	-3.9%
Malicious damage to property	26,106	24,850	-4.8%
Robbery with aggravating circumstances	33,404	30,768	-7.9%
Common assault	42,866	38,889	-9.3%
Assault with the intent to inflict grievous bodily harm	40,168	36,417	-9.3%
Robbery of cash in transit	47	42	-10.6%
Stock theft	6 853	6 089	-11.1%
<i>Illegal possession of firearms and ammunition</i>	3 607	3 184	-11.7%
Arson	853	732	-14.2%
All theft not mentioned elsewhere	69,556	59,646	-14.2%
<i>Drug-related crime</i>	43,344	35,932	-17.1%
Theft of motor vehicle or motorcycle	11,163	9 240	-17.2%
Burglary at non-residential premises	18,384	15,215	-17.2%
Shoplifting	14,412	11,597	-19.5%
Burglary at residential premises	51,004	40,568	-20.5%
Common robbery	12,262	9 549	-22.1%
Theft out of or from motor vehicle	27,810	20,111	-27.7%
<i>Driving under the influence of alcohol or drugs</i>	19,330	8 583	-55.6%

**Source:** (Gov, 2021)

## **2.10 THE ROLE OF SOCIAL WORK IN PREVENTING THE ABUSE AND KILLING OF PWA**

Social work is a practice-based profession that is embedded in legislative frameworks aimed at promoting social change and development, social cohesion, and the empowerment and liberation of people to improve their lives and wellbeing (NASW, 2008; International Federation of Social Workers, 2014). This profession promotes social justice, human rights, collective responsibility and respect for diversities of all human beings (International Federation of Social Workers, 2014). Within the ambit of social work people, communities, organisations and structures are engaged to address and contest challenges they are confronted with to improve upon these irrespective of gender, age, health status, race, creed, religion, and sexuality. Additionally, environmental factors and the consequences thereof are also addressed by the social work profession. In addition, social values, including social justice, service, integrity, dignity, self-worth, interpersonal relationship and competence all form part of social work commitment to serving humanity (NASW, 2008:19). In terms of mental health, social workers, according to the South African Mental Health Care Act (17 of 2002 section 1: xvii), should assist individuals with psychological problems together with psychologists, medical practitioners and nurses. In the context of people with albinism with mental health challenges, social workers are well-trained and suited to address such.

Based on the above explanation of the roles of the social work profession, it is important to understand that there are several cases of people facing traumatic events such as the abuse of people living with albinism. It is therefore important, as a social work profession, that the study clearly highlighted the role of social workers in the disaster planning, response, and recovery phases. In fact, social work as a profession, has already played an important role in the disaster field, as many are informed, trained, and experienced in the basic skills necessary to respond. This is evidenced by the fact that nearly half of the cases that relate to abuse, trauma which lead to mental problems require health services which are mostly delivered by social workers worldwide because they are affiliated with these (Federal Emergency Management

Agency, 2016).

Significantly, it is important to understand that social workers have the potential to bring a unique understanding to the disaster field by underscoring the values of the social work profession and giving attention to oppressed and disadvantaged populations. This perspective is vital for the development of individual, family, and community response plans. In simpler terms, social work as a profession is very effective as an intervention strategy and brings the required responses to disaster-related cases. Given the increase in all types of communal disasters, it's no surprise that other disciplines have also acknowledged the need to firm up the necessary concepts and theories, response plans and interventions, and to solidify best practices and evidence-based responses at the micro to macro levels (Bauwens & Naturale, 2017).

Globally, social workers have been involved with natural disasters, epidemics, pandemics and discrimination and are accustomed to addressing and dealing with complex, multifaceted phenomena such as albinism. This means that they are involved in relief work and are accustomed to using their skills to co-ordinate often chaotic circumstances which warrants utilising and engaging with various stakeholders to achieve a positive outcome for all the parties concerned. Psychosomatic concerns, post-traumatic stress disorders (PTSD), stress, anxiety and abuse have been managed by social workers using therapy and counselling to bring healing, social change and to enhance people's lives. Having said that, social workers play a huge role in environmental issues that increasingly affect people's well-being, both locally and globally. Dominelli (2012) highlighted the role social workers play in addressing environmental challenges in various communities. Despite the profession lagging behind on environmental challenges, its involvement has been impactful on communities (Gray, Coates & Hetherington, 2013).

People with albinism frequently encounter abuse, threats, discrimination and killing, which psychologically and emotionally scars them and affects their self-confidence and

self-esteem (Smith & Mackie, 2007). Self-esteem refers to a person's subjective emotional evaluation of their self-worth, which can be negative or positive (Smith & Mackie, 2007). In the case of people with albinism, societies' and community members' perceptions and treatment of them can result in negative evaluations of themselves. In the circumstances of people with albinism, social workers are able to counsel them and their friends, family members, children or partners when they have experienced or observed, or heard about abuse or murder of people with albinism. Social workers do this with care, sensitivity, respect, dignity, compassion, unconditional acceptance, and confidentiality. Additionally, people with albinism who feel rejected by their family, friends, partners or society can also access counselling to work on their confidence and self-esteem (Coleman, 2018).

## **2.11 RESEARCH GAP**

Several qualitative studies have been conducted on people with albinism in South Africa and will be shared to highlight research gaps that this study intended addressing:

- Franklin, Lund, & Bradbury-Jones, (2018). Children with albinism in African regions: their rights to 'being' and 'doing'.
- Mazibuko & Kromberg, (2018). A Personal perspective: Living with albinism.
- Mswela, (2017). A selection of legal issues relating to persons living with albinism.
- Mswela, (2017). Violent attacks against persons with albinism in South Africa: A human rights perspective.
- Ngubane, (2020). An ethical analysis of the African traditional beliefs surrounding people living with albinism in South Africa.
- Mbatha, (2021). Trafficking in persons living with albinism in South Africa.

Worth noting is that studies conducted on the abuse and killing of people with albinism have been mostly conducted in African countries other than South Africa (Kajiru & Mubangizi, 2019). One could assume that this is due to the number of people with

albinism being higher in those countries than those in South Africa. However, the credibility of the statistics poses a challenge as current statistics conducted over the past four years are not forthcoming. In addition, there are more studies conducted from a biomedical perspective than a psycho-social one. Although several studies have been conducted on albinism and people with albinism, this study differs as it addresses the contributory factors of the abuse and brutal killing of people living with albinism, investigates the coping strategies of people with albinism after experiencing abuse and observing, hearing about or witnessing killings, and to develop intervention strategies to combat the abuse and killings of people with albinism. In this study, emphasis is placed on how the social work profession can assist and the role that social workers can play in awareness, counselling and managing affected people with albinism.

## **2.12 CONCLUSION**

This section of the chapter addressed the factors that lead to the abuse and killing of people with albinism, including that cultural beliefs and myths attribute magical powers and sub-human characteristics to people with albinism. Due to misconceptions and myths, people with albinism globally and in South Africa face a stigma and various forms of discrimination and abuses/violations. The following chapter presents the theoretical framework that guided the study.

## CHAPTER 3: THEORETICAL FRAMEWORK

### 3.1 INTRODUCTION

The preceding chapter presented and discussed the literature review on the abuse and killing of people with albinism. This chapter discusses the theoretical framework suitable for addressing the abuse and killing of people with albinism and commences with an explanation of a theoretical framework.

According to Kumar (2014), a theory is a model that acts as the framework of assumptions and concepts in which it is embedded. It serves as an outline or guide for modelling a structure. A theoretical framework is widely used to guide a researcher in his or her investigation in a broad field of expertise by expounding an underlying principle, rationale or foundation with respect to the research topic (Khan, 2010). In other words, a theoretical framework is used as a systematic diagram which shows how the study believes the variables should relate among each other (Awang, 2011). According to Neuman (2011), a theoretical framework is objectively geared towards enhancing clarity, appropriateness and effectiveness in research. The two authors defined a theoretical framework as that part of a research proposal or study that sets out to describe the research question and the line of inquiry and methodology used to answer it. For Ocholla and Le Roux (2011), a theoretical framework refers to the agenda, outline, and theoretical construct of a research approach and normally precedes the literature review. Thus, concepts and constructs are used at a theoretical level while variables are used at the empirical level as explanations or interventions. As such, theories are generalisations about variables and the relationships among them. This study was underpinned by the Ecological Theory and Resilience Theory. The study used the two theories because they describe and predict the phenomenon under study. The following section describes how the two theories were formulated and how they apply to the current study.

### **3.2 Ecological Systems Theory**

The Ecological Systems Theory was developed by Urie Bronfenbrenner (1977). Ecological Systems Theory, also called development in context or human ecology theory, identifies five environmental systems with which an individual interacts. The theory offers a framework through which community psychologists and social workers examine individuals' relationships within communities and wider society (Bronfenbrenner, 1977). The theory is also commonly referred to as the ecological/systems framework. The ecological theory guides the study by providing it with an accurate and relevant lens in order to get understanding of the importance of dealings between people who are living with albinism and the society in which they live, on daily basis.

It is important to understand that all people here on earth relate to their environment through interactions with one another. It means that interaction begins within and from their homes, work, social rules, just to mention a few. People come across one another in groups, organisations, and other systems in which the person makes contacts (Kirst-Ashman & Hull, 2010:11). The aforementioned perspectives suggest that people who are living with albinisms' abuse and killing come from the aforementioned components and they have a very crucial influence on their lives. It is of paramount important for an individual to have a sound understanding of the "person-in-the environment" (KirstAshman, 2010:12). The environment in this context is the interaction of people living with albinism and other people around them. In other words, the environment might have a negative or positive way in which it perceives these people.

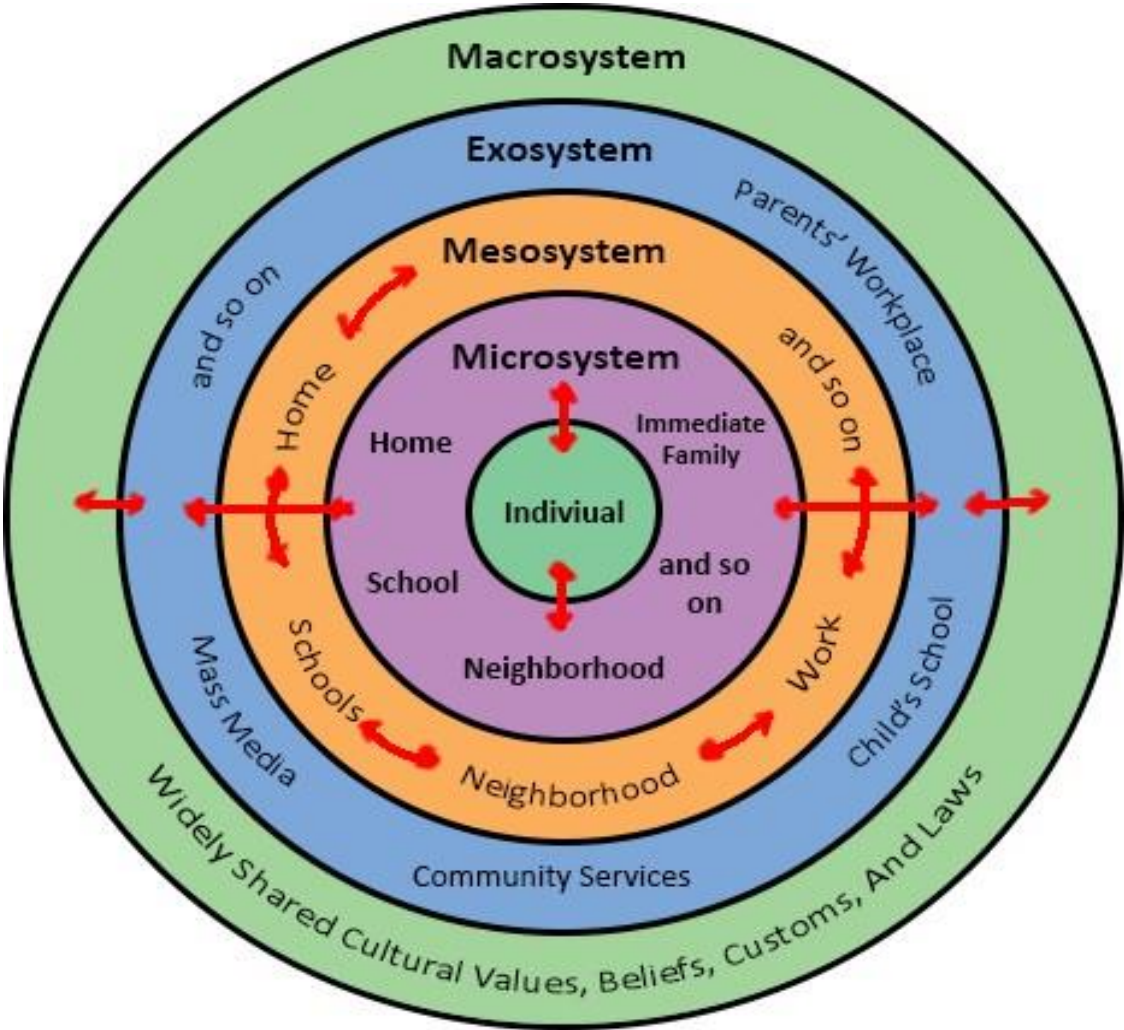
It is equally crucial from the ecological viewpoint that there is a need to understand two important concepts, which are "input" and "output" (Kirst-Ashman & Hull, 2010:12). Input means that an individual applies pressure on and abuse to the people living with albinism, which turns out to be an emotional and mental problem to them. What that means is that people living with albinism find themselves under a lot of pressure and are unable to cope with the pressure caused by the social environment in which they interact, thus it is termed the output. The aforementioned statement brings an important

analysis in an attempt to address the psychosocial dilemma experienced by PWA. There is a strong and urgent need to address and reduce the abuse and killing as well as the cruelty towards albinos (input) to reduce the emotional and mental experiences associated with them (output).

According to the ecological perspective, it is key to understand the interface. The word interface means an interaction of an individual with the environment where that individual lives. The environment needs to be identified and changed for good in order to enable people who are living with albinism to live in a way that is conducive and humanly comfortable for them, instead of living as prey to a lion (Kirst-Ashman, 2010:12). On the other hand, it is crucial to understand the ecological perspective as adaptation and coping. The two concepts do not favour people living with albinism due to a lack of protection from the public environment in which they live. The environment in which they live is harmful to their lives, thus addressing such is important. The terminology of adaptation is regarded as “the ability to adjust to the new conditions” whilst coping means “a form of human adaptation and implies a struggle to overcome problems” (Zastrow & Kirst-Ashman, 2013:30). It is important to note that in order for change to take place in the lives of people living with albinism, there is an urgent need for social workers to take a bold step and address and counsel those people with albinism who are traumatised by the abuse and brutal killings. Clearing the environment in which people with albinism live is of paramount importance as that will make their environment conducive for them to be treated like any other human beings and have a right go anywhere they want, at any time.

The ecological theory is relevant in this study as it enables social practice in KwaZulu-Natal, South Africa, to put the focus on how to completely minimise the depression and anxiety caused by some of the members of the public to people living with albinism. It is very important to create a mutual understanding between the public and victims of abuse. The study used the ecological theory in order to equip and assist social workers to consider the mechanisms necessary in this regard for those people who are living

with albinism, their families and the communities in which they live, as well as ensuring a lawful system is available (See figure 3.1).

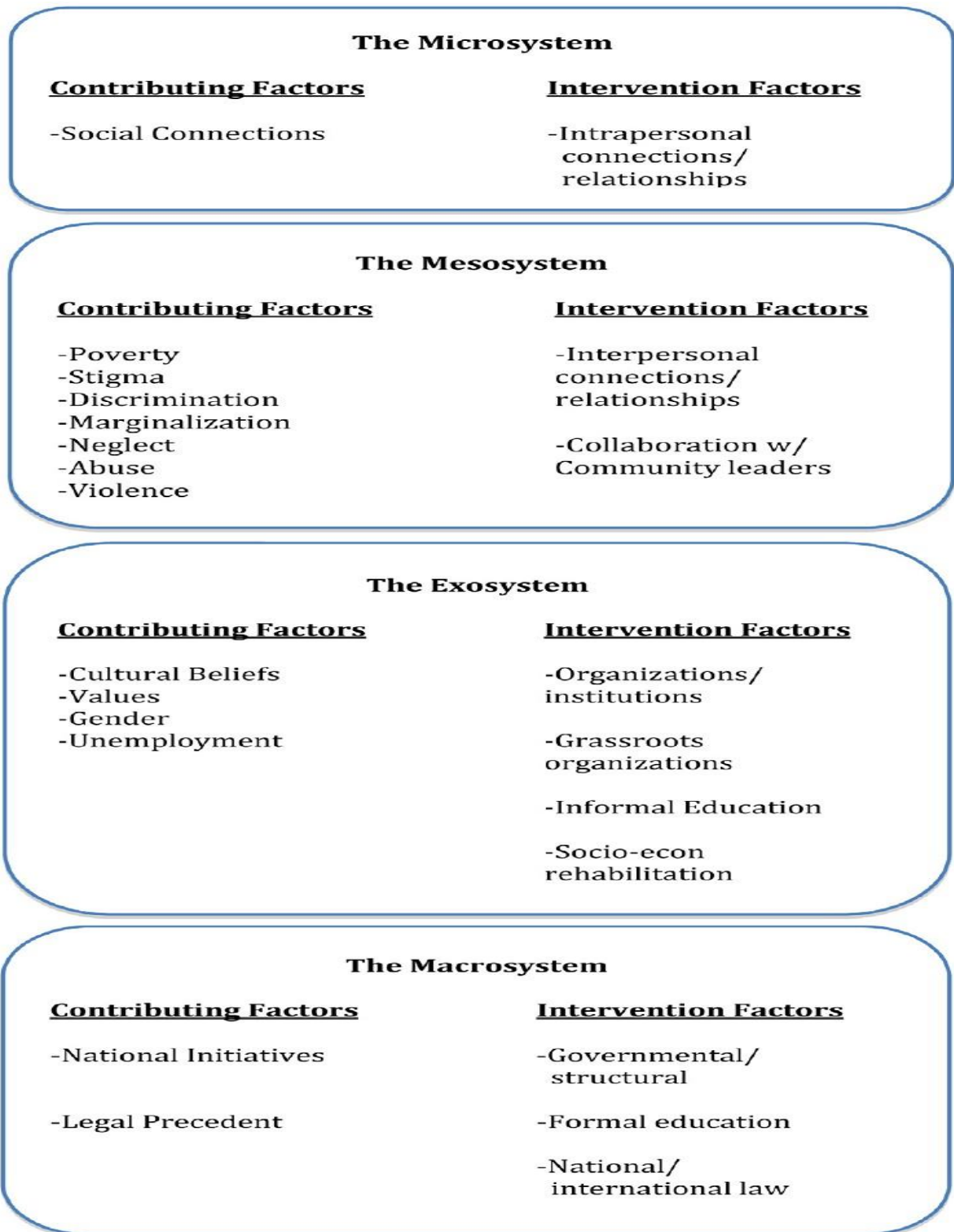


**Figure 3-1: Bronfenbrenner's Ecological Systems practice perspective**

(Source: <https://za.pinterest.com/pin/463800461603068348/>)

The ecological systems practice perspective diagram above illustrates that an individual is surrounded by other individuals for him/her to survive. The diagram can inform and help social work professionals locate and classify coping resources either as internal or external resources. This plays a foremost role in understanding the difficulties faced by people living with albinism and probable interventions that are applicable to the profession of social work at large. It is clear that the social work profession should use all available resources to ensure that problems faced by people

living with albinism are fully addressed, especially the psychological one.



**Figure 3-2: Bronfenner's ecological systems theory applied to PWA context**

**Source:** (Mostert & Weich, 2017).

### **3.3 Limitations of Ecological Systems Theory**

It is crucial to emphasise that like other ideas, Bronfenbrenner's theory contains some flaws. As a result, Leventhal and Brooks-Gunn (2000) pointed out that one of the shortcomings of the Ecological Systems Theory is that it concentrates primarily on interactions between communities and a child's family, leaving mesosystems understudied. According to Leventhal and Brooks-Gunn (2000), the extent to which mesosystems can impact infant development is unknown. Another flaw in Bronfenbrenner's theory is that it is difficult to test empirically. This means that the ecological systems appear well-established and successful from afar, but it is unclear if the systems are the direct cause of the observed results. Bronfenbrenner's theory has been criticised for assuming that persons who do not have robust and positive ecological systems are lacking in development. While this may be true in some circumstances, a great percentage of people can nonetheless grow into well-rounded persons without the help of their natural environments. Having said that, it is an exaggeration to assume that everyone who grows up in impoverished places of the world would have a negative development. Similarly, if a child's teachers and parents do not get along, the child may not notice any bad consequences if he/she is unconcerned. Even though Bronfenbrenner's theory has limitations like other theories, this does not imply that the theory is not applicable in this study. The study adopted this theory because it meets the goal of the study.

### **3.4 The relevance of Ecological Systems Theory**

The researcher found the Ecological Perspective Theory very useful in guiding and helping social workers understand their clients' problems, in this case people who are living with albinism. The theory emphasises an individual and the environment in which that individual lives (Kirst-Ashman, 2010:11). In the province of KwaZulu-Natal, where a majority of PWA reside, the ecological theory seems to be a well-oiled mechanism suiting the Social Development Organisation where social workers address the

problem of their clients. It is crucial for social work practice to apply this because it relates to the person-in-the environment in which he/she lives and the assessment can be done to find out how PWA are affected by or coping with the abuse and killing by the public where they live. The assessment in this context would mean that social work professionals would have time with an individual who has experienced the trauma of abuse from and killing by the public by analysing how that affect the lives of all people living with albinism and the legal measures that need to be taken. While social workers are dealing with that, they will be able to define the stress levels of these people and how they should intervene as professionals. The ecological perspective is therefore key in this matter as it is able to inform relevant interventions (Teater, 2010:27).

The researcher took the advantage of the Ecological Systems Theory because it is able to point out a clear picture on how people should relate to and treat one another in the environment in which they live. Additionally, the ecological theory draws a picture of the environment which distresses individuals who live in that environment and how they are affected in the same environment (Johnson, 2008:3). The researcher considers the Ecological Theory as one of the most appropriate in understanding the unfavourable experiences of abuse of people living with albinism in the province of KwaZulu-Natal. In that light, the study took advantage of the Ecological Theory because it has been able to provide an analysis of how people living with albinism relate to other people in the same environment in which they are, and the assets in that same area. It can be concluded that the Ecological Theory considers the way people are dealing with each other within a community, either positive or negative, and is able to bring a solution to the problem affecting the people in that community.

### **3.5 Resilience Theory**

The researcher also used the Resilience Theory by (Masten, Best, & Garmezy, 1990). The concept of resilience has been widely adopted to mean three different types of phenomena: (a) individuals who have experienced traumatic events but have been able to recover well; (b) persons who belong to high-risk groups, but who have more favourable outcomes than expected; and (c) persons who show positive adaptation,

despite life stressors (Masten, Best, & Garmezy, 1990). Resilience is generally considered to be a positive adaptation after a stressful or adverse situation (Hopf, 2010). In other words, resilience is applicable to a person who has been bombarded by daily stress, abuse or trauma caused by a particular seen where the person got disrupted in his/her internal and external sense of balance, presenting challenges as well as opportunities. It can be said that resilience is the integrated adaptation of physical, mental and spiritual aspects in a set of good or bad circumstances, a coherent sense of self that is able to maintain normative developmental tasks that occur at various stages of life (Richardson, 2002). Contrasting other models, the resilience theory stresses strengths over problems. It underscores dealings between the developing person and the social and physical environment in which a person lives. One of the advantages of resilience is that it enables an individual to have the ability to adapt to changing conditions and withstand and rapidly recover from disruption due to emergencies (Francis & Bekera, 2014:6).

The study took advantage of Resilience Theory because it is able to address issues of people who have been traumatised by a loss of a beloved person and those abused emotionally and physically, which in this case are people with albinism who are being abused and murdered in South Africa, particularly in KZN Province. Resilience Theory is not only about overcoming a deeply stressful situation, but also coming out of the said situation with competent functioning. Resiliency allows a person to rebound from adversity as a strengthened and more resourceful person (Hopf, 2010). In other words, people with albinism will be compelled to bounce back to their normal senses once they receive counselling from professional social workers.

According to Kisiel, Conradi, Fehrenbach, Torgersen and Briggs (2014), resilience is an effective tool for neutralising events, such as traumatic events, like sexual or physical abuse, witnessing domestic or community violence, or being in a natural disaster, which often cause children to have strong, upsetting feelings which can potentially disturb daily life and create a feeling of depression after the murder of relatives. It is widely acknowledged that after a fearful event that one has experienced

in life, there is need for counselling in order to regain strength to help them adjust and recover. Other people take time to adjust after experiencing a trauma, however, it is not the fault of the people if they do not bounce back quickly but it is a sign that they are unable to overcome the traumatic experience.

It is important to understand that not all people respond positively after a traumatic event; to some it is overwhelming thus it takes time to adjust and have the ability to recover (Kisiel, Conradi, Fehrenbach, Torgersen & Briggs, 2014). One of the consequences of trauma is that it takes time for a victim to adjust and return to a usual level of functioning. For example, if it is a child or an adolescent who has experienced trauma in life, that will affect some certain areas of his/her life (e.g., school performance), while at the same time showing resilience in other areas, for example peer relationships. In such cases, the support from social workers can play a pivotal role in ensuring that emotional support is provided in order for the victim to bounce back to a normal level of functioning. On the other hand, family and system resources, services and support can help improve functioning in areas in which the child is struggling, while also supporting and enhancing areas in which the child is doing well (Patterson, 2002).

### **3.5.1 Factors that are Effective in Enhancing Resilience in Both Adults and Children after Traumatic Events**

There are several factors that are effective in enhancing resilience in both adults and children after experiencing traumatic events. Both adults and children's resilience may be enhanced by these factors:

- Support from professional social workers;
- Support from professional psychologists;
- Support from parents, friends, family, school, and community;
- Resources that help to buffer negative consequences on daily life;
- Feeling safe at home, at school, and in the community;
- Having high self-esteem—an overall positive sense of self-worth;

- Possessing a sense of self-efficacy—a child’s belief that he/she can be successful in different areas of life;
- Having a sense of meaning in one’s life, which might include spiritual or cultural beliefs, connections with others, or goals and dreams;
- Possessing talents or skills in certain areas (e.g., the arts, athletics, academics); and
- Possessing a variety of adaptive and flexible coping skills that he/ she can use in different situations (Brom, Pat-Horenczyk & Ford, 2009).

### **3.6 Limitations of Resilience Theory**

As with any other model, Resilience Theory has limitations, which we reviewed briefly in this section. As a result, Lemay (2004) expressed worry that Resilience Theory may be criticised for focusing too much on an imagined desirable end rather than on the disadvantages. For the majority of people, resilience also has a breaking point. Multiple hazards and stressors can erode resilience on an individual, interpersonal, and larger society level. For instance, despite their specific qualities, an abuse survivor may feel better during treatment but may relapse and engage in harmful habits to cope (Robinson, 2013). Even while this theory, like others, demonstrated shortcomings, it did not exclude this study from adopting a theory of this sort. It aided the study in determining how people with albinism can be addressed in order for them to recover from their trauma.

### **3.7 The Relevance of Resilience Theory in the Study**

Resilience Theory was used in this study because it is a strength-based intervention that focuses on helping youth and families recognise, understand and value their own strengths in responding to a traumatic event (Masten, 2001). Professional social workers frequently encounter clients or victims with a history of trauma, which is defined as an exposure to an extraordinary experience that presents a physical or psychological threat to oneself or others and generates a reaction of helplessness and fear (American Psychiatric Association [APA], 2013). The exposure may have occurred

in the distant or recent past, and pervasive symptoms such as intrusive thoughts of the event, hyperarousal to stimuli in the environment, negative moods, and avoidance of cues related to the trauma are characteristic of both acute and chronic posttraumatic stress disorders (APA, 2013). Traumatic experiences take many forms, but they typically involve an unexpected event outside of a person's control, such as criminal victimisation, an accident, natural disaster, war, or exposure to community or family violence.

Professional social workers help abused people like people with albinism who are being abused in many different ways to discuss their painful memories and reduce anxiety to a more tolerable level, and to increase their ability to modulate emotion and behaviour (Cohen, Mannarino, Kliethermes, & Murray, 2012). As such, social workers allow people with albinism to express themselves in many different ways in order to develop trust, choice, collaboration, and empowerment across treatment modalities so that clients can experience healthy relationships with a professional supporting them (Harris & Fallot, 2001; Elliott, Bjelajac, Fallot, Markoff, & Reed, 2005). Trauma-informed social workers appreciate how common trauma is, and that violence and victimisation can affect psychosocial development and lifelong coping strategies; they emphasise client strengths instead of focusing on pathology, and they work on building healthy skills rather than simply addressing symptoms. The professional social worker uses his/her experience to recognise the emotional vulnerability of trauma survivors, and most importantly, the social worker avoids inadvertently repeating dynamics of abusive interactions in helping the victim narrate the event (Knight, 2015; Morrison, et al., 2015).

Professional social workers use trauma-specific interventions aimed at reducing symptoms resulting from the negative sequelae of trauma in the life of the individual. The victims of abuse, which in this case are PWA, are encouraged to connect with others, to be respected, and to become hopeful regarding their own recovery (Bloom & Farragher, 2013; SAMHSA, 2013). Recognising that presenting problems, in actuality, often are indicators of trauma and interrelated emotional wounds, trauma-

informed social workers develop partnerships with clients in a way that empowers them. Instead of interpreting this response as hostility, lack of motivation, or resistance to services, social workers should view it as a normal protective reaction when an individual feels vulnerable. Social workers recognise that the burden is on them to facilitate trust and that this requires a compassionate and respectful way of engaging with clients. Professional social workers must ensure the following happens with clients:

- Establishing an association;
- Identifying strengths as well as problems;
- Instilling hope and encouragement;
- Finding practical solutions to presenting problems;
- Building strengths and competence; and
- Fostering empowerment and change

### **3.8 Conclusion**


The use of the Resilience Theory and the Ecological Systems Theory as the theoretical framework for the study proved suitable as they complemented each other as both acknowledged the individual, their systems and environment and assisted in analysing the collected data, together with the research questions, the reviewed literature and the ultimate aim of the study.

## **CHAPTER 4: RESEARCH METHODOLOGY**

### **4.1 INTRODUCTION**

The previous chapters provided international, national and local literature on the topic under study and the theoretical framework which guided the study. This chapter presents the roadmap of the research processes, strategies and rationale utilised and executed in this study. It focusses on the development of intervention strategies to address the abuse and brutal killing of people with albinism in KwaZulu-Natal. Methodology within the social sciences refers to the processes associated with “understanding how knowledge about such phenomena can be generated” (Grønmo, 2020: 30). Methods articulate the processes used “for the planning and implementation of specific scientific studies” (Grønmo, 2020: 30). The researchers’ perspective on the philosophical research paradigm, approach, methodology and methods chosen are reflected in Table 4.1 below:

**Table 4-1: Research Paradigm, Research Approach, Research Methodology and Research Methods**



How to acquire knowledge about reality?	How can knowledge be acquired	What processes are used to acquire knowledge?	What techniques are used to acquire knowledge?
<p><b>Based on:</b></p> <p><b>Ontology:</b> Assumptions &amp; beliefs about the nature of reality (i.e. what is reality); and</p>	<p>Includes:</p> <p><b>Deductive reasoning:</b> formulate theory or hypothesis then testing;</p>	<p>Includes:</p> <p><b>Quantitative:</b> measuring numeric variables;</p>	<p>Includes:</p> <p><b>Timeframe (prospective, retrospective</b></p>
<p><b>Epistemology:</b> Assumptions &amp; beliefs about the nature of knowing (i.e. how to know reality?)</p>	<p><b>Inductive reasoning:</b> construct theory &amp; hypothesis from data; and</p> <p><b>Combination of deductive and inductive reasoning's.</b></p>	<p><b>Qualitative:</b> analysing meanings, concepts &amp; patterns; and</p> <p><b>Mixed:</b> combining quantitative &amp; qualitative methodologies according to the research goals</p>	<p><b>or cross-sectional);</b></p> <p>Population &amp; Sampling;</p> <p><b>Data collection; and Data analysis</b></p>

(Adapted from: Bannister-Tyrrell & Meiqari, 2020)

In addition, the chapter comprises of:

- a) Introduction
- b) Aim, objectives and research questions
- c) Research paradigm, research design and research approach, population, sampling, data collection, data analysis and ethical considerations.

## **4.2 RESEARCH PARADIGM**

A research paradigm refers to the manner in which the world can be viewed, a system of ideas which describes or explains a topic and constitutes the "...entire constellation of beliefs, values, techniques, and so on shared by members of a given community," (Kuhn, 1970:175). An advantage of using paradigms is their ability to position the research lens in a manner that organises reality (Maree, 2016). Though several research paradigms exist, the three most common paradigms are positivism, interpretivism and pragmatism. Paradigms are comprised of ontology, epistemology, axiology and methodology.

The interpretivism paradigm assumes that reality is multiple, intangible, dynamic and socially and historically constructed by the human mind based on peoples' experiences of the world. Pandya (2012) mentioned that an individual's reality is local and specific and can be changed with new information. The interpretivism paradigm considers the importance of what people think, feel and see and produces an understanding of the context of the information system, and the process whereby the information system influences and is influenced by the context.

After many literature searches and much introspection regarding which paradigm was best suited to achieve the aim and objectives of the study, the interpretivism paradigm was considered well- suited. This paradigm is primarily used in qualitative studies due to their heavy reliance on the reality of people and participants by focusing on their experiences to understand phenomenon. The primary reason for the use of an

interpretivism research paradigm is its reliance on participants' views of their situation or experiences and of the research. A study conducted by Maree (2016) further mentioned that research projects addressing participants' experiences, emotions, opinions and ideas is highly dependent on qualitative research. This is in addition to its ability to understand and reconstruct the constructions that people and the researcher initially hold, aiming towards consensus but yet open to new interpretations with new information and analysis and its effectiveness in investigating everyday experiences (Neuman, 2011; Kumar, 2014).

The study afforded key informants a chance to narrate their daily experiences by using their own vocabularies to guarantee quality and relevant data. Moreover, this paradigm provided the researcher with an opportunity to gather an understanding of how people who are living with albinism felt when experiencing the abuse from their community members and how it affected them psychologically. In the context of this study, people with albinism's lived experiences, opinions, challenges and emotions regarding the abuse and killing of people with albinism was relevant to develop an intervention strategy that could address these horrendous acts.

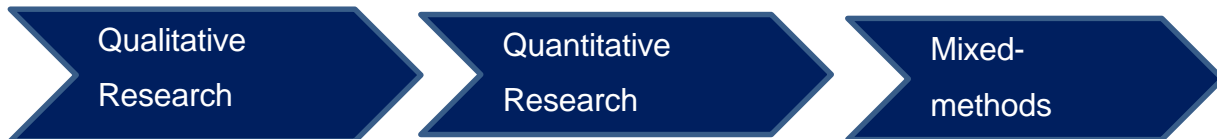
**Table 4-2: Assumptions of the Interpretivist Paradigm**

<b>Assumption</b>	<b>Interpretivist Paradigm</b>
<p><b>Ontology</b> The nature of reality in this study is shaped by the experiences of participants and contexts.</p>	<p>Participants' reality of the murder and brutal killing of people with albinism.</p>
<p><b>Epistemology</b> The relationship between the researcher and participants' subjective interpretations of the phenomenon under study.</p>	<p>The researcher conducted 26 in-depth face-to-face interviews with people with albinism and 10 interviews with social workers. A subjective interaction was facilitated, for thick data to maximise the study findings.</p>
<p><b>Axiologic</b> The role of values in this study.</p>	<p>Subjective interactions and values were evident in this study.</p>
<p><b>Methodology</b> How did the researcher obtain the data?</p>	<p>A phenomenological qualitative approach was used in the study as participants shared their unique experiences and perceptions of the abuse and brutal killing of people with albinism's in in-depth interviews.</p>

### 4.3 RESEARCH APPROACH

A research approach is the plan comprising several systematic steps that detail the data collection, analysis and interpretation of collected data. Hence, its reliance on a study problem, aims, objectives and research questions. In addition, to achieving the study aims and objective it is paramount that researchers choose the relevant approach/es. Three primary research approaches exist, namely: qualitative, quantitative and mixed methods (Creswell & Creswell, 2017). These are summarised in Table 4.3 below:

**Table 4-3: Summary of Research Approaches**



Subjective	Objective	Combination
<b>Reasoning:</b> inductive	<b>Reasoning:</b> deductive	Combination
Researcher constitutes the research instrument	Independent of the researcher	Combination
<b>Research Design:</b> Case study, action research, narrative research, Grounded Theory, ethnography, Phenomenology. Interpretivist, Hermeneutic	<b>Research Design:</b> Experimental, non-experimental (surveys), quasi-experimental, random-controlled trials (RCT). Positivist, objectivist, empiricist, nomothetic, descriptive.	<b>Research Design:</b> Combination
<b>Data required:</b> Textual data Required	<b>Data required:</b> Numerical data required	<b>Data required:</b> Textual and numeric
<b>Responses:</b> Open-ended	<b>Responses:</b> Closed-ended	<b>Responses:</b> open and closed ended
<b>Used to:</b> explore, make meaning and understand human and social challenges and phenomenon through: experiences, understanding, realities, opinions, attitudes, circumstances, behaviours and feelings	<b>Used to:</b> measure, explain, predict, quantify and link variables Test theories by examining variables	<b>Used to:</b> integrate qualitative and quantitative data to attain an outcome that either one cannot on their own
<b>Responds to:</b> Why, What and How? Questions	<b>Responds to:</b> 'how much' or how many'? questions	<b>Responds to:</b> qualitative & quantitative questions
<b>Sample:</b> Smaller	Sample: Larger	<b>Sample:</b> Combination
<b>Data collection tools:</b> Interviews, observation, focus group discussions	<b>Data collection tools:</b> Surveys, questionnaires,	<b>Data collection tools:</b> Combination of qualitative and quantitative tools

After careful consideration of the three main types of research approaches, the study assumed a qualitative approach to best articulate the abuse and killing of people with albinism. This was due to participants volunteering their observations,

experiences, understanding, opinions, feelings and attitudes on the phenomenon under study (Kumar, 2014). Hence, adopting this approach resulted in rich, thick, stimulating information being collected which contributed to robust recommendations being tabulated to develop intervention strategies to address this societal ill that is imposed on PWA (Braun & Clarke, 2013).

#### **4.4 RESEARCH DESIGN**

A research design is "...a strategy for addressing the research question including specification for enhancing the study's integrity," (Creswell, 2014:42). This study used a phenomenological research design. This type of research design chronicles phenomena through the eyes/lens of individuals who have observed or experienced it as its aim is to outline how and what observations and experiences are shared (Teherani, et al., 2015). As the study participants were PWA, they were considered best able to provide their lived experiences of the phenomenon under inquiry (Creswell, 2014).

Cognisance was taken of the advantages and disadvantages of a phenomenological research design. The advantages included: assists in understanding participants meaning of a phenomenon, incorporating new meanings, ideas and issues in real time, developing new theories and the retrieval of organic data; while the disadvantages of this design were that the data collection process could be time-consuming and requiring resources, challenging data interpretation and analysis processes, difficulties in managing the research progress and the subordinate credibility attached to phenomenological studies. However, the phenomenological design proved relevant to draw on their experiences without any interference from other research populations thus accumulating their unique experiences through their words (Neuman, 2011). This method enabled the researcher to source concise and clear information from people with albinism.

## **4.5 RESEARCH SETTINGS**

The areas demarcated for the study were the eThekweni Metropolitan Municipality (TMM) and uMgungundlovu District Municipality (UDM) located in KwaZulu-Natal province. The province is the second most populated province in South Africa and consists of 11 municipalities, of which eThekweni is the sole metropolitan municipality with Amajuba, Harry Qwala, Ilembe, King Cetshwayo, Ugu, Umgungundlovu, Umkhanyakude, Umzinyathi, Uthukela and Zululand being district municipalities.

### **4.5.1 eThekweni Metropolitan Municipality**

eThekweni is the only metropolitan municipality in KwaZulu-Natal and houses the province's largest city, eThekweni. This is the third biggest city in South Africa with two of the busiest ports in Africa and is a tourism hub due to its subtropical warm climate and beautiful beaches.

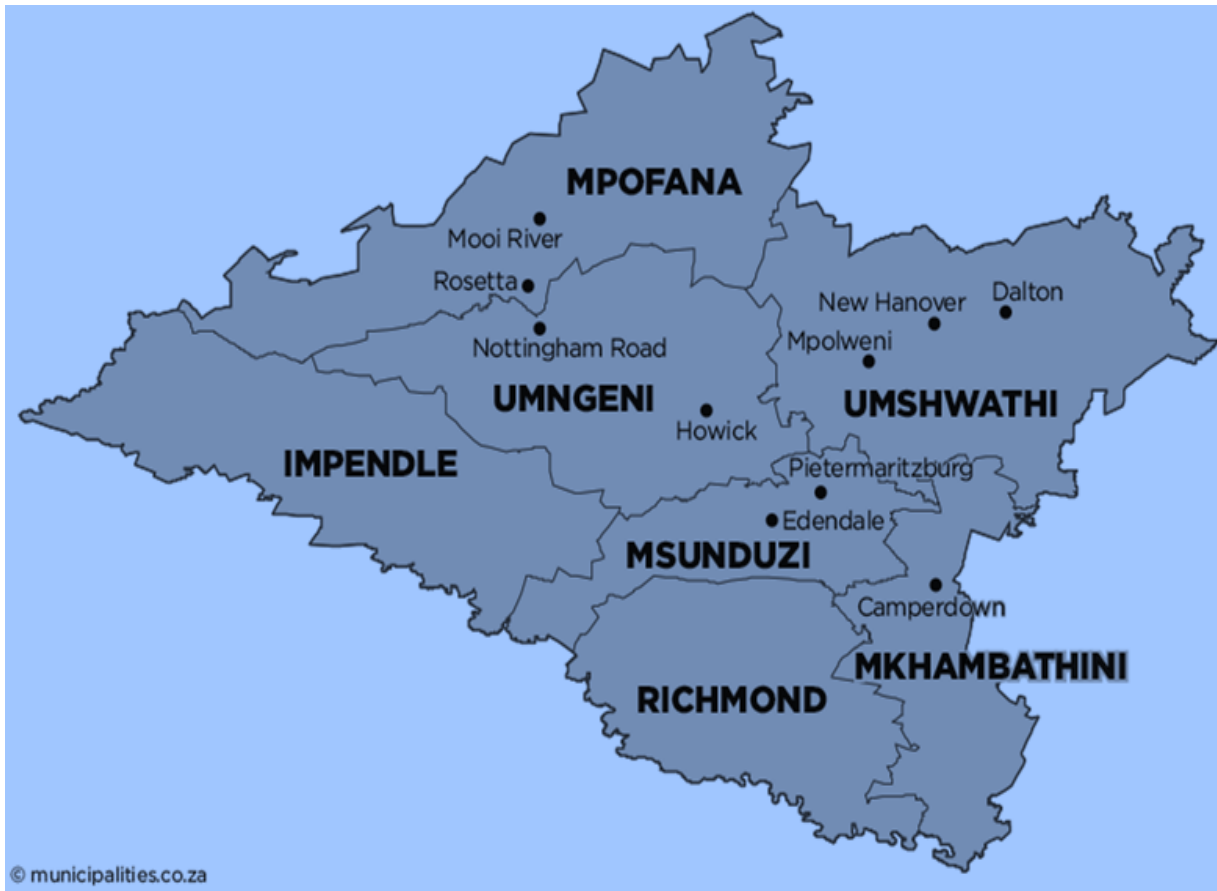


**Figure 4-1: eThekweni Metropolitan Municipality**

Source: [www.municipalities.co.za](http://www.municipalities.co.za)

#### **4.5.2 uMgungundlovu District Municipality**

The uMgungundlovu District Municipality consists of seven (7) local municipalities some of which are located in neighbouring towns: Mpofana – Mooi River, Impendle – Impendle, Mkhambathini – Camperdown, Msunduzi – Pietermaritzburg, Richmond – Richmond, uMngeni – Howick, and uMshwathi – New Hanover/Wartburg ([www.municipalities.co.za](http://www.municipalities.co.za)). The province hosts the capital city, Pietermaritzburg and the legislature is located in this area of KwaZulu-Natal. This municipality is the third largest GGP (Gross Geographical Product) contributor.



**Figure 4-2: uMgungundlovu District Municipality**

Source: [www.municipalities.co.za](http://www.municipalities.co.za)

The two municipalities were chosen as the study setting as they have recorded large numbers of people with albinism who have been abused and murdered (Statistics South Africa, 2011:2). Statistics South Africa (2011) reported that approximately 5,000 people with albinism are in KZN, with most living in eThekweni Metropolitan Municipality and uMgungundlovu District Municipality.

## **4.6 STUDY POPULATION, SAMPLING, STUDY SAMPLE, SELECTION AND RECRUITMENT**

### **4.6.1 Study Population**

A population refers to, “the total number of people, groups or organisations that could be included in a study,” (Bertram & Christiansen, 2020:71). Study populations are selected or sampled based on their experience regarding the subject matter being researched (Creswell & Creswell, 2017). In other words, their selection is not a matter of pure chance but the intentional recruitment. This is to attain rich and reliable information on the abuse and brutal murdering of people with albinism (Kumar, 2014).

For this study’s purpose, the population included people with albinism and social workers living and working in eThekweni Metropolitan Municipality (TMM) and uMgungundlovu District Municipality in KwaZulu-Natal. As previously mentioned, the people with albinism population in KwaZulu-Natal is estimated to be at 5,000 in KwaZulu-Natal with a large number of people with albinism living in eThekweni and uMgungundlovu Municipalities.

### **4.6.2 Sampling**

#### **4.6.2.1 Study Sample**

Qualitative researchers engaging an interpretivism research paradigm are concerned with collecting comprehensive, in-depth data rather than “statistical accuracy or ...whether their data are representative of an entire population,” (Bertram & Christiansen, 2020:72). In addition, a qualitative sample size relies on data saturation which occurs, “... in data collection and analysis when new incoming data produces little or no new information to address the research question,” (Guest, Namey & Chen, 2020:2). Moreover, Guest, Namey and Chen (2020) highlighted the controversy surrounding data saturation. Hence, the researcher decided to operationalise data saturation by documenting how data saturation was reached. Therefore, although the study population represents all the people with albinism and social workers living and

working in the two municipalities, the study sample refers to the sample that can be recruited from the study populations. This was due to all people with albinism and social workers in the municipalities not being able to participate in the study.

#### **4.6.2.2 Inclusion and Exclusion Criteria**

The inclusion and exclusion criteria for the people with albinism and the social workers are as follows:

#### **4.6.2.3 People with albinism**

Inclusion:

- Be a people with albinism, older than 18 years who had observed, heard about or experienced abuse or the murder of people with albinism and is willing to voluntarily participate in the interviews.

Exclusion

- Individuals not meeting the inclusion criteria.

#### **4.6.2.4 Social Workers**

Inclusion

- Social workers from the Department of Social Development (DSD) at eThekweni and uMgungundlovu Municipalities who have been involved in counselling people with albinism who had observed, heard about or experienced abuse or murder of people with albinism for two years and more. This was to ensure that these participants had experience of the phenomenon under study.

Exclusion

- Social workers who did not meet the inclusion criteria.

#### 4.6.2.5 Sampling Procedure

Sampling refers to the process of considering a few and manageable number of individuals that are representative of a larger population (Kumar, 2014). Hence, the relevance of choosing a sampling method well-suited to the study. The sampling method that the study applied was chosen based on the population of the study, which included people with albinism and social workers in Welfare (Social Development) who had two and more years' counselling and dealing with people with albinism who had or were experiencing abuse. Kumar (2014: 382), and Moule and Goodman (2014: 291) highlighted that one of the advantages of sampling is its ability to logically pick, "cases for inclusion in a research project". In that case, a non-probability, homogeneous, purposive and snowball sampling strategy were employed.

Notably, in non-probability sampling, participants are carefully chosen, based on the experience they have pertaining to the subject being researched. Moreover, snowball and purposive sampling facilitated the relevant sample of participants required to address the phenomenon as they had the required experience (Creswell, 2014). This study used purposive sampling to obtain a suitable sample as this technique allows the selection of participants with similar characteristics to comprehensively answer the study's research questions. Purposive sampling is also referred to as selective judgmental, selective, or subjective sampling (Kumar, 2014).

The researcher used people with albinism and social workers as participants in Durban Metropolitan and Pietermaritzburg in the province of KZN, as cases of abused and murdered people with albinism are highly reported there. The researcher's approach derived its support from Hammond and Wellington (2013). In addition, Kumar's (2014) assertion that purposive sampling utilises experts' judgement to assume reliable and purposes information rendered this type of sampling suitable. In that regard, purposive sampling was chosen as people with albinism and social workers working with them have reliable information regarding the abuse and murder of people with albinism. People with albinism articulated what occurs in their community and to them, social workers are best able to report on incidents of people with albinism coming to them for counselling

after being traumatised or abused. Additionally, the study considered people with albinism and social workers as the main participants of the study due to their wealth of information and knowledge on the topic being sufficient to support the study. Kumar (2014) concurred that purposive sampling enables researchers to be judgemental when choosing the population to be included. In that light, the researcher chose to use social workers who are well informed cases of abuse of people with albinism and those people with albinism who experienced or witnessed the abuse and killings of their fellow brothers and sisters. In this case, people with albinism were the most suitable for the study because they have depth information about their abuse in various communities' and society which would provide valuable and reliable information.

Neuman (2011:90) highlighted that purposive sampling is relevant where participants and geographical areas are intentionally selected to conduct studies. Thus, the study purposively sampled people with albinism due to the abuse and killing of people with albinism in these areas and social workers dealing with cases of people with albinism who were or had experienced abuse in eThekweni Metropolitan and uMgungundlovu District municipalities. The two districts were chosen because cases of abuse and murder of people with albinism are highly reported there.

Snowball sampling involves the assistance of the study participants in obtaining other potential participants, especially where it is difficult for the researcher to gain access to the population. This sampling technique is used by researchers to develop a sample of a special population by asking an initial set of informants to supply names of potential sample members to participate in a study. This type of sampling consists of stages as the researcher first identified two people with albinism who met the inclusion criteria.

The researcher requested to be assisted by two people who were living with albinism to identify those who once experienced or witnessed abuse to participate in the study. Fortunately, all those who were asked to participate in the pilot study agreed to voluntarily participate and they also met the inclusion criteria (Neuman, 2011). The reason for the study to have a pilot study was to test if the questions prepared for the participants were clear and participants would understand what the study wanted from

them.

### Sample Sources



Figure 4-3: Sample Sources

## 4.7 DATA GENERATION

Data collection refers to the manner in which researchers collect or generate data from the study participants. However, in this study, the term *data generation* is chosen over *data collection* as this study assumes a qualitative, interpretivist paradigm which entails the participants creating (their perceptions, perspectives, opinions, words and emotions) the data. As this study assumed a qualitative exploratory approach to understand people with albinism and social workers who deal with and counsel people with albinism who experienced or are experiencing abuse, the data collection tools had to provide access to in-depth information to comprehensively unpack their opinions, feels,

emotions and perspectives.

#### **4.7.1 Data Generation Tool**

A data generation tool allows us to systematically collect information about our objects of study (people, objects, phenomena) and the settings in which they occur. In other words, it is the manner in which empirical evidence will be generated from the source (participants). It includes questionnaires, interviews, observations, surveys, focus group discussions (FGD) just to mention a few (Pickard, 2013).

#### **4.7.2 Semi-structured Interviews**

Due to the sensitive nature of the study, data was collected in the form of participant-consenting, dual-recorded, semi-structured interviews, utilising an open-ended interview guide (Appendices 4 and 5). A research interview refers to a social reciprocal interaction between a participant and the data generator (researcher) with the explicit aim of obtaining relevant information to achieve the research aim and objectives (Hammond & Wellington, 2013). Moreover, in the context of this study, the interviewees orally responded to the researcher's questions and probes that addressed the objectives and research questions in the face-to-face interviews (Kumar, 2014). An advantage of using interview schedules is that it has semi-structured questions that make it easier for researchers to gather useful information to achieve the research objectives (Pickard, 2013).

Semi-structured interviews were used to collect data from both social workers and people with albinism. Interviews enable participants to engage in a "reflective process" to "explore his/her experience in detail and reveal the many features of that experience...", (Stringer, 2014:105). The researcher acknowledged the participants as "experts and "by allowing them to re-tell their stories regarding the abuse and brutal killing of people with albinism. The open-ended questions for the people with albinism were initially written in English and translated into isiZulu language as most of the inhabitants of both municipalities were isiZulu speaking - English language is not their

mother-tongue. However, the professional social workers' questions were also written in English and isiZulu. Both participant groups were allowed agency by choosing which language they wanted the interviews to be conducted in.

### **4.7.3 Data Generation Preparation**

#### **4.7.3.1 Pre-test and Pilot**

Pre-testing and piloting are relevant preparatory interventions used to ensure the accuracy and relevance of the data collection tool. Though these processes are predominantly conducted in quantitative studies, several qualitative studies have conducted them (Castillo-Montoya, 2016; Dikko, 2016). In the context of this study, the interview guide was piloted with two people with albinism and two social workers. The pilot interviews spanned between 45 minutes and one hour in the home/offices of the two interviewees. This was to identify any limitations, gaps, insensitivity and shortcomings and to adjust and refine the interview guide prior to the semi-structured interviews commencing (Castillo-Montoya, 2016). In addition, it assisted the researcher to improve upon his interviewing skills. The two people with albinism who participated in the pilot interviews were not participants in the actual study.

#### **4.7.3.2 Research Assistant**

One of the people with albinism who participated in the pilot study agreed to be a research assistant in the study. His suitability was based on him being a people with albinism, being available for two months to generate data and being a people with albinism activist which allowed him access to various populations of people with albinism and to facilitate a trust component with the participants and him being multilingual (isiZulu, IsiXhosa and English). In addition, he knew many people with albinism in and around his home and was familiar with the data generation tool. However, the research assistant only participated with people with albinism interviews and not with the social worker interviews as he articulated that he had not used social work services and had no expert knowledge on that target population. The research assistant participated in

the planning and preparation for the data generation process by ensuring sufficient consent forms, the printing of information letters, both voice-recorders were charged and had extra batteries, refreshments, stationery and tissues were packed in the case prior to the collection of data.

#### **4.7.3.3 Gaining Access**

The researcher had to negotiate with the Chief (Induna) in some tribal authorities to generate data from the people with albinism which is an important step in field work as buy-in needs had to be received from the relevant gatekeepers for the researcher to conduct the study (D’Cruz & Jones, 2014:104). The Department of Social Development (DSD) granted the researcher an opportunity to collect data from social workers, while an ethical clearance was received from the University of Zululand (See Appendix 1 & 2). Hence, all relevant protocol, permission and ethical consideration were pursued and obtained prior to data collection commencing.

### **4.8 DATA GENERATION**

The data generation process took place between June and July 2021 in the two municipalities. Most of the interviews took place during the day in social workers’ offices or boardrooms and in the homes of the participating people with albinism’s homes, with all Covid-19 protocols fully observed as the levels of movement had been revised during the data generation period and are documented in Table 4.4 below:

**Table 4-4: Alert Levels for Data Generation Period**

Date	Covid-19 Level
26 July -	Adjusted alert level 3
28 June – 25 July 2021	Adjusted alert level 4
16 June - 27 June 2021	Adjusted alert level 3
31 May -15 June 2021	Adjusted alert level 2

**Summary of alert levels**

<b>ALERT LEVEL 5</b>	<b>ALERT LEVEL 4</b>	<b>ALERT LEVEL 3</b>	<b>ALERT LEVEL 2</b>	<b>ALERT LEVEL 1</b>
 <b>OBJECTIVE</b>				
Drastic measures to contain the spread of the virus and save lives.	Extreme precautions to limit community transmission and outbreaks, while allowing some activity to resume.	Restrictions on many activities, including at workplaces and socially, to address a high risk of transmission.	Physical distancing and restrictions on leisure and social activities to prevent a resurgence of the virus.	Most normal activity can resume, with precautions and health guidelines followed at all times.  Population prepared for an increase in alert levels if necessary.

WHATSAPP SUPPORT  
**0600 123 456**  
 EMERGENCY NUMBER  
**0800 029 999**  
[sacoronavirus.co.za](https://www.sacoronavirus.co.za)



**Figure 4-4: Summary of Alert Levels**

Source: [www.gov.za](http://www.gov.za)

The study considered data saturation when collecting data from people with albinism. The data saturation was important because researchers who find that the data does not capture newer information, it then considered a point of saturation (Leedy & Ormond, 2005). In that light, Leedy and Ormrod (2010) posited that a scientific method of a manageable size of any population may range from 0.5%. It was based on the above clarification that the study also considered only 0.5% of the total size of the population of 5,000. The 0.5% was considered as the total population of the study, yet in mind the researcher had full understanding of data saturation. As expected, the point

of saturation was reached and the study consisted of 26 people with albinism.

The researcher also interviewed social workers from welfare (social development) in Durban and Pietermaritzburg, who were fully experienced in counselling people who were survivors of abuse and potential killing. The recruitment inclusion criteria referred to social workers with two years and more counselling experience with people with albinism as newly recruited social workers may have lacked the counselling skills to counsel the people with albinism. Prior to the commencement of each interview, the researcher introduced himself and the research assistant and provided information regarding the interview process, ethics, voluntary informed consent, the use of dual voice-recorders, the potential of the research, and the dissemination of the research outputs. In addition, the services of social workers at welfare and DSD offices had been sourced and obtained in case any participant required this due to the sensitive nature of the study. From the onset, all participants requested pseudonyms as most of the participating people with albinism felt they were living targets and speaking out under their correct name could contribute to further abuse and/or killing. The tables below show the data generation process which included 36 participants (26 people with albinism and 10 social workers).

**Table 4-5: People with albinism participants**

Code	No.	Name (pseudonym)	Age	Gender	Race	Municipality	Language
P1F	1.	Victim 1	18-30	F	BA	eThekwini	IsiZulu
P2F	2.	Victim 2	18-30	F	BA	eThekwini	IsiZulu
P3F	3.	Victim 3	18-30	F	BA	eThekwini	IsiZulu
P4F	4.	Victim 4	18-30	F	BA	eThekwini	IsiZulu
P5F	5.	Victim 5	18-30	F	BA	eThekwini	IsiZulu
P6F	6.	Victim 6	18-30	F	BA	eThekwini	IsiZulu
P7F	7.	Victim 7	18-30	F	BA	eThekwini	English
P8F	8.	Victim 8	18-30	F	BA	eThekwini	Isizulu
P9F	9.	Victim 9	18-30	F	BA	eThekwini	Isizulu
P10F	10.	Victim 10	31-40	F	BA	eThekwini	Isizulu
P11F	11.	Victim 11	31-40	F	BA	eThekwini	Isizulu
P12M	12.	Victim 12	18-30	M	BA	eThekwini	Isizulu
P13M	13.	Victim 13	18-30	M	BA	eThekwini	Isizulu
P14M	14.	Victim 14	18-30	M	BA	eThekwini	English
P15M	15.	Victim 15	31-40	M	BA	eThekwini	Isizulu
P16M	16.	Victim 16	31-40	M	BA	eThekwini	English
P17M	17.	Victim 17	18-30	M	BA	eThekwini	IsiZulu
P18F	18.	Victim 18	18-30	F	BA	uMgungundlovu	IsiZulu
P19F	19.	Victim 19	18-30	F	BA	uMgungundlovu	IsiZulu
P20F	20.	Victim 20	18-30	F	BA	uMgungundlovu	IsiZulu
P21F	21.	Victim 21	18-30	F	BA	uMgungundlovu	IsiZulu
P22F	22.	Victim 22	31-40	F	BA	uMgungundlovu	IsiZulu
P23F	23.	Victim 23	31-40	F	BA	uMgungundlovu	English
P24F	24.	Victim 24	31-40	F	BA	uMgungundlovu	Isizulu
P25M	25.	Victim 25	18-30	M	BA	uMgungundlovu	Isizulu
P26M	26.	Victim 26	18-30	M	BA	uMgungundlovu	Isizulu

The table above denotes that the population was comprised of 18 females and eight males with eThekwini Metropolitan Municipality participants being skewed in favour of 11 females and six males, and uMgungundlovu District municipality being represented by seven females and two males. There were 19 participants between the ages of 18-30 years, with only seven being between the ages of 31-40 years. Additionally, 24 participants had lived in KZN for more than 10 years with only two having lived there between 7-10 years. The table shows that 20 participants had a high school and tertiary qualification - 10 had completed between Grades 10-12 of high school, and only 10 had completed their tertiary education, while another 10 had completed from Grades 7-9 and another 10 had completed Grades 4-6. Finally, three participants reached between Grades 4-6 and another three had reached between Grades 7-9. These

findings demonstrate that PWA are serious about their education, like other people.

**Table 4-6: Social Workers – Participants**

Code	No.	Name (pseudonym)	Age	Gender	Race	Municipality	Language
SW1F	1.	Therapist 1	30-40	F	BA	eThekwini	English
SW2F	2.	Therapist 2	30-40	F	BA	eThekwini	English
SW3F	3.	Therapist 3	30-40	F	C	eThekwini	English
SW4F	4.	Therapist 4	30-40	F	BA	eThekwini	English
SW5M	5.	Therapist 5	30-40	M	BA	eThekwini	English
SW6F	6.	Therapist 6	41-50	F	I	uMgungundlovu	English
SW7F	7.	Therapist 7	30-40	F	BA	uMgungundlovu	English
SW8F	8.	Therapist 8	30-40	F	BA	uMgungundlovu	English
SW9M	9.	Therapist 9	30-40	M	BA	uMgungundlovu	English
SW10M	10.	Therapist 10	41-50	M	BA	uMgungundlovu	English

Table 4.6 depicts the social workers who were participants in this study. In that light, four were females from eThekwini Metropolitan, while three other females were from uMgungundlovu district municipality. One male was from eThekwini Metropolitan and two other males from the uMgungundlovu district municipality. Additionally, seven of the social workers were aged between 31-40 years, while two were aged 41-50 years. Regarding qualifications, eight had a BA Degree in Social Work, and two had a Masters in Social Work. Finally, five social workers had worked between 2-5 years, while three had worked between 6-10 years and two had worked 11 years and above more.

The use of purposefully-worded, open-ended interview guides (Appendices 4 and 5) that were guided by the study aim, objectives and research questions, facilitated free-flowing dialogues that allowed for further probing to attain comprehensive data. The dual voice-recorders were fully charged voice recorders prior to the interviews and were only used once signed permission was obtained from participants. This was to ensure all information was captured and acted as a preventative measure in cases where electricity load-shedding took place. All the participants agreed to the use of voice-recorders. The interview guides and consent forms were in English and isiZulu. However, participants were granted agency to choose in which mode of language they

wanted the interviews to be conducted. In addition, the research assistant was fully conversant in isiXhosa. However, no participants requested this service on offer. These options were offered in an endeavour to be respectful of all the participants and to be culturally and linguistically sensitive. The research assistant further added to the comfort levels of the people with albinism participants during the interviews. To assess the comfort levels of participants, the researcher constantly enquired about this and maintained eye contact.

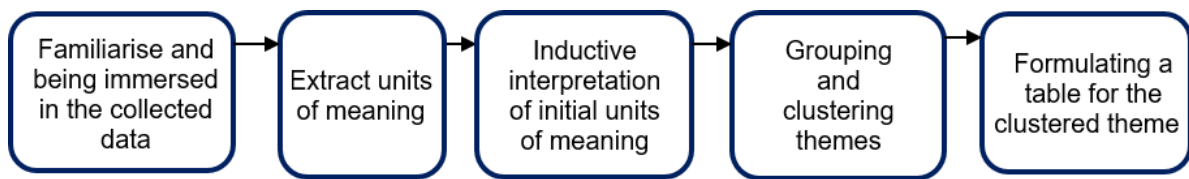
Notes were also taken during the interviews as it facilitated better data analysis as the information was already accessible and made it easier to categorise and classify them accordingly and allow for accurate capture of the discussion (Pickard, 2013). After each interview with a people with albinism. the researcher and research assistant discussed and noted non-verbals and other observations to ensure the full interview was captured and to triangulate the findings.

#### **4.9 DATA ANALYSIS**

Data are “materials collected or generated that are analysed” (Braun & Clarke, 2013:329). Hennink, Hunter and Bailey (2012:205) described qualitative data analysis as: “A process of immersion in data, through which you can identify and interpret the experiences of your study participants. It involves a process of discovery that enables you to remain close to the data and form an evidence-based understanding of the research issues”. This study pursued an Interpretive approach which is: “a qualitative research approach committed to the examination of how people make sense of their major life experiences’ (Smith, Flowers & Larkin, 2009:1). This approach was chosen as “... human beings are sense-making creatures, and therefore the accounts which participants provide will reflect their attempts to make sense of their experience,” (Smith, Flowers & Larkin, 2009:4). Moreover, Smith and Osborn (2008) stressed its relevance to study’s that explore personal experiences that are of a complex and sensitive nature.

Due to the dynamic nature of IPA, the researcher was able to assume the participatory

role of correctly articulating the participants' voices, make meaning of their contributions and decode such meanings. This process is known as dual interpretation or a double hermeneutic process (Pietkiewicz & Smith, 2012). This is in an endeavour to understand people with albinism and social workers' views and experiences from their perspective. During this process, the researcher utilised his interpretations and perceptions to make sense of the abuse and brutal killing of people with albinism, hence rendering his role an active one by closing the participant-researcher gap to articulate their voices in an accurate and comprehensive manner. The use of IPA allowed the analysis process to comprehensively capture participants' perceptions and meanings of the phenomenon under study to develop an intervention strategy to reduce and eliminate the abuse and murder of people with albinism.



**Figure 4-5: Interpretivism Phenomenological Analysis (IPA)**

#### **4.9.1 Familiarising and Being Immersed in the Collected Data**

The researcher listened to each voice recording several times to fully acquaint himself with each participant's perspective. Once he was fully conversant with the participants recorded inputs, he transcribed the data verbatim himself. Thereafter, all 26 transcripts were reread in anticipation of themes emerging and shared with the research assistant.

#### **4.9.2 Extract Units of Meaning**

This step entailed extracting units of meaning by creating a table a) containing the researchers interpreted meanings of participants excerpts for each participant and b) inductive interpretation of participants' perspectives.

### **4.9.3 Inductive interpretation of Initial Units**

Here, the researcher assigned clustered themes to information containing the researcher's interpreted meanings of each participant's excerpts and constantly vying back and forth with the initial meaning to ensure that it was adequately captured.

### **4.9.4 Grouping and Clustering Themes**

This stage entailed the researchers clustering the identified themes according to similarity and relatedness aligned to the study objectives. This stage required attention to detail and insight of the researcher. Hence, this stage was lengthy and resulted in the researcher consulting academics who were fully conversant with this process.

### **4.9.5 Formulating a Table for the Clustered Themes**

In this final stage of IPA, the researcher developed a table to insert the final clustered themes after consultation and continuously revisited the themes and created sub-themes to interpret the collected data. More detail of the process is found in the next chapter as these themes and findings are related to Chapter 2 (literature review) and Chapter 3 (theoretical framework).

### **4.9.6 Interpretative Phenomenological Analysis and Self-Reflexivity**

Due to the researcher having worked with people with albinism in his capacity as a social worker and the research assistant being a person with albinism, cognisance of their positionality, biases and experiences was noted from the onset of the study. To counteract any biases and prejudices, both the researcher and the research assistant implemented reflexive bracketing, resulting in them temporarily bracketing out their personal experiences and attitudes towards the study phenomenon (abuse and brutal killing of people with albinism and they attended reflexivity meetings regularly. This

was for the duration of the study and due to them recognising that they were not participants in the study but researchers and their goal of attaining a rigorous study was close to them both (Chan, Fung & Chien, 2013).

The research team members used daily meetings to discuss their reflexivity, positionality and insider-outsider roles, conducted debriefing and used two reflexive journals to document incidents. In addition, the primary investigator (PI) held debriefing sessions with an academic from another institute of higher learning who did not form part of the study. The research assistant received debriefing from an organisation primarily dealing with people with albinism. Though participants and researchers have different roles they share the research space (Engward & Goldspink, 2020); cognisance was also noted that utilising IPA involved the researchers interpreting gathered data and analysing it through their lens. The research team members' feelings and thoughts are documented in the next chapter while discussing the findings.

#### **4.10 TRUSTWORTHINESS**

The trustworthiness of a study is central to the research process as it constitutes the epicentre of qualitative research to which academic scholars and audiences seek in order to pay attention to and take the study and its findings seriously, as truly represented data (Rubin & Babbie, 2011; Nyirenda, Kumar, Theobald, et al., 2021). The elements that are central to the trustworthiness of a study are: dependability, transferability, credibility and confirmability (Forero, Nahidi, De Costa, et al., 2018) and are explained in Table 4.7, as the Four Dimensions Criteria (FDC). The FDC refers to Lincoln, Lynham and Guba's criteria to ensure a rigorously sound and systematic research study (Schou, Hostrup, Lyngso, et al., 2012; Morse, 2015; Lincoln, Lynham & Guba, 2011; Forero, et al., 2018).

**Table 4-7: Four-Dimensions Criteria (FDC)**

CRITERIA	APPLIED STRATEGIES TO ACHIEVE A RIGOROUS AND ROBUST STUDY
<p><b>Dependability</b> The stability of findings over time. Dependability involves participants' evaluation of the findings, interpretation and recommendations of the study such that all are supported by the data as received from participants of the study.</p>	<ul style="list-style-type: none"> <li>• Rigorous record keeping</li> <li>• Reflexive Journal</li> <li>• Interview Notes and Note taking</li> <li>• Interview Recordings and transcripts</li> <li>• Universal Serial Bus (USB)</li> </ul>
<p><b>Transferability</b> The degree to which the results of qualitative research can be transferred to other contexts or settings with other participants. The researcher facilitates the transferability judgment by a potential user through thick description</p>	<ul style="list-style-type: none"> <li>• Comprehensive interviews utilising semi-structured interview guides to probe to attain rich, thick data</li> <li>• Comprehensive reports</li> <li>• Key Concepts were clearly defined</li> <li>• Purposive sampling – study settings and participants</li> </ul>
<p><b>Credibility</b> The confidence that can be placed in the truth of the research findings. Credibility establishes whether the research findings represent plausible information drawn from the participants' original data and is a correct interpretation of the participants' original views</p>	<ul style="list-style-type: none"> <li>• 1-month engagement with stakeholder in various communities to become familiar with the context, settings and gatekeepers, and build relationships.</li> <li>• 2-months' data collection process until saturation achieved.</li> <li>• Dual voice recorders</li> <li>• Research Assistant and researcher</li> <li>• Reflexive meetings</li> <li>• Peer debriefing with academic outside the university</li> <li>• Notepads</li> <li>• Observations of RA and PI</li> <li>• Triangulation – Interviews were carried out on various days and times of the week and day, with different sources (people with albinism and social workers), Primary investigator was not a person with albinism while the RA was a person with albinism.</li> <li>• Two researchers were involved with the coding.</li> <li>• The PI transcribed the voice recordings and then shared with the RA for accuracy.</li> </ul>
<p><b>Confirmability</b> The degree to which the findings of the research study could be confirmed by other researchers. Confirmability is concerned with establishing that data and interpretations of the findings are not figments of the inquirer's imagination, but clearly derived from the data</p>	<ul style="list-style-type: none"> <li>• Pilot</li> <li>• Observation</li> <li>• Coding</li> <li>• Concepts comprehensively defined</li> <li>• Systematically documenting the research process and steps from inception until the end. Apply data and document management of data for the next five years.</li> <li>• Notes, recordings, transcripts</li> <li>• Comprehensive report</li> </ul>

**Source:** (Forero et al., 2018)

## The Four-Dimension Criteria was Adapted to Include a Fifth Dimension, Reflexivity

<p><b>Reflexivity</b> The process of critical self-reflection about oneself as researcher (own biases, preferences, preconceptions), and the research relationship (relationship to the participant, and how the relationship affects participant's answers to questions).</p>	<ul style="list-style-type: none"><li>• Using reflexive meetings and diaries/journals to confront the researcher and research assistant's positionality in the study and how they affect/impact on the research process and data gathering</li></ul>
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### 4.11 ETHICAL CONSIDERATIONS

Ethics refer to what conduct or behaviour is correct or incorrect in the research and relates to “practices concerned with ensuring we do research in moral and non-harmful manner,” (Braun & Clarke, 2013:330). To further ensure trustworthiness, ethical considerations were ensured prior to and throughout the study. Ethical clearance (Appendix 1) was sought and received from the University of Zululand's Research Ethics Committee (UZREC 171110-030 PGD 2021/7). The Department of Social Development (DSD) (Appendix 2) provided permission to conduct the study with social workers in the two municipalities. All 36 participants voluntarily signed consent forms (Appendix 3). People with albinism completed their demographic data in Appendix 4 while social worker participants completed their demographic data (Appendix 5). The interview guides for the two sets of participants were attached to Appendix 4 and 5 respectively. Participants were not allowed to participate in the interview unless the study process had been explained to them and they had voluntarily consented to participate in the study. They were also informed that they would receive no stipend for participation and that they could choose to leave the study at any time without any consequences, and that all collected data was confidential with the exception of it being seen by the researchers' supervisors (Flick, 2014).

#### 4.11.1 Gaining Access

The researcher had to negotiate with the Chief (Induna) to collect data from the people with albinism in tribal authority land. This is very important in research as the first step

in field work and all authorities need to agree to the researcher conducting the study in the area (D'Cruz & Jones, 2014:104). On the other hand, a letter asking for a permission to collect data from the Department of Social Development was approved (See Appendix B).

#### **4.11.2 Informed Consent**

The informed consent was used by the researcher and research assistant to explain the aims and objectives of the study and for all the participants to be made aware of their agency regarding whether they should participate in the study (Creswell, 2014:34). This was explained in isiZulu to people with albinism and English to the social workers.

Additionally, their withdrawal from participating in the interviews bore no consequences or punishment. Study participants were informed of the sensitivity and emotionally-charged aspects of the study and that the researcher had negotiated the services of social workers to assist should they so need. The use of the dual voice-recorders was explained, and their permission was sourced prior to the interviews taking place.

#### **4.11.3 The Right to Privacy**

Participants' privacy was observed and respected in the study by stressing the importance of confidentiality and the use of pseudonyms and anonymisation as the "information collected from the participants of the study is not revealed in the form that it can be linked or traced back to the individuals (Creswell, 2014). The personal details, such as participants' names and addresses, to name a few, were not inserted on any documents that would be in the public domain. Hence, pseudonyms were utilised to protect anonymity. Participants were assured that the data gathered was solely for research purposes, including the dissemination of data in the form of research articles, conference proceedings and workshops, all aimed at bringing awareness to the plights of people with albinism.

#### **4.11.4 Reflexivity, Positionality and Insider-Outsider**

Reflexivity in the research context includes being cognisant and critically reflecting on one's attitudes, feelings and emotions hence the researcher continuously reflects upon his/her positionality to ensure transparency and to avoid any biases (Palaganas et al., 2017; Rosenbluh, 2017; Dodgson, 2019). Since the researcher is from a different district municipality, Kwa-Nongoma, he was considered an outsider in terms of him not being a person with albinism and not forming part of the communities in which the study was conducted, whereas the research assistant was an insider in terms of his albinism. However, the researcher could relate to their experiences as he had spent several years counselling people with albinism who had experienced or been traumatised by the abuse and killing of people with albinism.

To avoid any power dynamics, namely *us and them*, both the researcher and research assistant dressed casually in an attempt to break down power barriers to create a warm, nurturing environment. The dress code and our use of simple terminology worked as the participants shared thick data with us, which at time was sensitive and emotive. The researcher did not discuss his previous interactions with other people with albinism to the participants and neither did the research assistant discuss his experiences, observations and conversations regarding the abuse and murder of people with albinism. This was where reflexive bracketing was initiated as the research assistant acknowledged his albinism and bracketed out his experiences, perspectives and feelings on the topic under study.

#### **4.12 CONCLUSION**

In this chapter, the research design, paradigm, approach and methodology, were discussed. including that it was a qualitative study that explored people with albinism and social workers' experiences and perspectives of the abuse and brutal killings of people with albinism. Purposive and snowball sampling were techniques used to gather data through semi- structured interviews, with an open-ended interview guide.

The interviews allowed the researcher to reach an in-depth understanding of all the participants' views on the abuse and the brutal killings of people with albinism to develop intervention strategies to address these atrocities. The ethical considerations of the study were discussed as well as the limitations. The next chapter provides an analysis of data.

## CHAPTER 5: DATA ANALYSIS AND SYNTHESIS PHASE: RESULTS

### 5.1 INTRODUCTION

The goal of this chapter is to report the findings of the data analysis, which was collected from people with albinism and social workers. This chapter comprises two sections: Part One and Part Two. Part One presents the collected data from the 26 semi-structured interviews with people with albinism who experience abuse or had previously experienced, observed or heard about the abuse and brutal killing of other people with albinism.

The study's findings are presented as symbolic representations of the participants' points of view guided by IPA.

The first section of this chapter is structured as follows:

- Participants demographic profiles
- Causes of abuse and brutal killing of people living with albinism
- Intervention strategies currently in place
- How people living with albinism cope with abuse and brutal killings of people living with albinism.
- Intervention strategies recommended to combat and eliminate the abuse and brutal killing of people with albinism.

Part Two of the chapter examined the data gathered from the semi-structured interviews with 10 social workers. Furthermore, IPA was used to analyse Part Two of the chapter. Part Two is structured as follows:

- Participants' demographic profiles
- Causes of abuse and brutal killings of people living with albinism
- Intervention strategies in place

- How people living with albinism cope with the abuse and brutal killings of people living with albinism.
- Intervention strategies recommended to combat abuse of people living with albinism
- Summary

## **5.2 PART ONE: DATA ANALYSES RELATED TO PEOPLE LIVING WITH ALBINISM**

### **5.2.1 Participants' Demographic Profiles**

Participants were required to respond to structured questions relating to their personal information, such as their gender, age, educational level, duration of time living in KwaZulu-Natal and their employment status.

**Table 5-1: Participants Demographic profiles – people with albinism**

Variable	eThekwini Metropolitan Municipality: n=17		uMgungundlovu District Municipality: n=9		TOTAL n=26
	Female	Male	Female	Male	TOTAL
<b>Gender</b>	11	6	7	2	26
<b>Age</b>	Female	Male	Female	Male	Total
• 41-50	0	0	0	0	0
• 18-30	9	4	4	2	19
31-40	2	2	3	0	7
Older than 50	0	0	0	0	0
Total	11	6	7	2	26
<b>Education Level</b>	Female	Male	Female	Male	Total
Grades R-3	0	0	0	0	0
Grades 4-6	2	0	1	0	3
Grades 7-9	0	1	2	0	3
Grades 10-12	4	1	3	2	10
<b>Tertiary education</b>	5	4	1	0	10
Total	11	6	7	2	26
<b>Duration participants have lived in KZN</b>	Female	Male	Female	Male	Total
24 months and less	0	0	0	0	0
2-3 years	0	0	0	0	0
4-6 years	1	0	2	0	3
7 -10 years	10	6	5	2	23
Total	11	6	7	2	26
<b>Employment Status</b>	Female	Male	Female	Male	Total
Student	5	3	1	1	10
Employed	3	2	2	0	7
Unemployed	3	1	4	1	9
Total	11	6	7	2	26

### 5.2.2 Gender Representation of the Participants

The people with albinism population consisted of males and females; Table 5.1 illustrates that the study sample was comprised of more females (18) than males (8) with eThekwini Metropolitan Municipality participants being skewed in favour of 11 females and six males and uMgungundlovu District municipality being represented by seven females and two males. Due to the unavailability of current statistics for people

with albinism, it was difficult to gauge if there were in fact more female people with albinism than males. However, worthy of noting is that while on recruitment drives in KZN, we observed and noted more females than males and younger males with albinism than older males.

### **5.2.3 Age Distribution of the Participants**

The majority (19) of the participants were between the ages of 18-30 years, with only seven being between the ages of 31-40 years. The findings by age indicated that people with albinism can live for 40 years or more, despite popular belief that they live for less than 30 years. This also concurred with the World Report (2019) which reported that people with albinism can live until at least 40 years or more.

### **5.2.4 Years Participants Have Lived in KZN**

Table 5.1 reflects that the majority (24) of the participants have lived in KZN for more than 10 years with only two (2) participants living in KZN for between 7-10 years. On further probing, these two participants reported that they were friends and due to the abuse of people with albinism they tended to always be in close proximity as they trusted each other to protect their lives, hence they had agreed to move to KZN to study. In addition, their choice of university was based on the large population of people with albinism studying at the university. One participant stated: *"We are safer in numbers."* The responses from the majority of the participants were that people with albinism tend to stay in an area or province for a long time, depending on the way they are treated, their acceptance and if they felt safe.

### **5.2.5 Educational Level of Participants**

The majority of the participants (people with albinism) (20) had attained a high school and tertiary qualification with 10 participants having between a Grade 10-12 high school qualification and only 10 who had completed tertiary education. Moreover, an

equal number (10) of the participants had obtained between Grade 7-9 qualification and (10) had reached between Grade 4-6. Moreover, there were three participants who had studied completed between a Grade 4-6 qualification and another three studied between a Grade 7-9. These findings demonstrated that people with albinism are serious about their education like other people. It was interesting to note that despite the challenges that some people with albinism are confronted with, they are still able to complete tertiary level education.

### **5.2.6 Participants Employment Status**

In terms of occupation, most of the participants were students with a score of 10. There were nine people with albinism who were unemployed. Lastly, the table above showed that only seven people with albinism in the study were employed.

### **5.2.7 THE ABUSE AND KILLING OF PEOPLE WITH ALBINISM**

It is important to note that prior to the interview addressing the abuse and brutal killing of people with albinism, it was important to ascertain the participants' awareness of the abuse against people with albinism and the types that they had experienced themselves. To address this and facilitate further open dialogue on the topic, two questions were asked to initiate free-flowing conversation and tease out the phenomenon under study.

1. Are you aware of the abuse and brutal killing of people with albinism?
2. Have you experienced abuse due to you being a person with albinism?

#### **5.2.7.1 Level of Awareness of the Abuse and Killing of People Living with Albinism**

The participants were asked about their level of knowledge of maltreatment directed towards people with albinism. Table 5.2 summarises the findings.

**Table 5-2: Level of Awareness of the Abuse and Killing of People Living with Albinism**

Variables	Frequency
Yes	26
No	0
Total	26

The study established that all 26 people with albinism were fully aware of the abuse and killing of people with albinism in KZN. These findings demonstrated a strong awareness of the abuse and killing of people with albinism, implying that the participants could have experienced or observed or heard about these acts. Franklin et al. (2018) also noted that awareness of maltreatment of people living with albinism is growing in Africa. In Africa, it is reported that people with albinism endure greater discrimination and difficulties than others (Reimer-Kirkham et al, 2019).

#### **5.2.7.2 Have You Experienced Abuse Due to you being a Person with Albinism?**

The participants were asked to provide their perspective on a closed-ended question (YES or NO) regarding their experience of abuse due to them being a person with albinism. Table 5.3 below summarises the findings.

**Table 5-3: Personal Experience with Abuse**

Variables	Frequency
Yes	26
No	0
TOTAL	26

According to the data in Table 5.3 above, all 26 people with albinism had experienced abuse as a result of the condition of albinism. This information was critical to the study

as participants had to have extensive knowledge of the subject to yield thick, rich data and for it to be aligned to the literature review and theoretical framework for analysis and conclusion purposes. Though the types and causes of abuse experienced by people with albinism were not objectives nor research questions, participants felt they needed to share the types of abuse they had experienced, heard about or witnessed and the causes from their perspective. The researcher was of the opinion that since the study was about people with albinism experiences, opinions and concerns, he should allow for self-determination by respecting their input.

Respect is an important component of the researcher-participant and social worker-client relationships. The findings of the study agreed with Kirst-Ashman and Hull (2010:12) in the Ecological Systems Theory in that people within a society put pressure on one another and that is considered as an input to the victim. The study's findings also corroborated with Tambala-Kaliati, Adomako, and Kwabena Frimpong-Manso' (2021) who also found that people with albinism have been subjected to brutal attacks in several African countries, particularly Malawi, throughout history for a variety of reasons. Larson (2011), Mswela (2013), Benyah (2017), and Mswela's (2017) studies also argued that people with albinism have lived with and experienced persecution, and various forms of abuse.

### **5.2.8 TYPES OF ABUSE EXPERIENCED DUE TO BEING A PERSON WITH ALBINISM**

It was important in the context of this study to determine the types of abuse experienced by people with albinism as all the participants had stated that they had previously experienced abuse.

#### **5.2.8.1 Name Calling and Labelling**

The study established that people with albinism are discriminated against due to their physical characteristics (skin colour, hair and eyes) and assigned labels. What was common to all 26 people with albinism was the discomfort they felt with being called

“albinos” and “person living with albinism”. They viewed both these terms or labels as derogatory, misleading, demeaning and an additional way of dehumanising them. Hosking (2008) further asserted that language is a potent tool for shaping beliefs and realities about people, things or places and can be degrading, demeaning and dehumanizing through taunting and name-calling. The term “albino” is commonly used to describe people with albinism due to it originating from the Latin word 'albus', meaning 'white (Hosking, 2008). These findings are also consistent with those of Brocco (2015) and Murray (2015), who reported that people with albinism experience and are subjected to taunting and discriminatory and derogatory labels due to their physical features and appearance, resulting in negative stereotypes being assigned to them.

Two participants articulated their feeling on the use of *albino* and *persons living with albinism* as follows:

*“Firstly, we Black, not white. We did not ask for this colour and all the bad things that go with this colour skin.”* (Participant#1).

*“I am constantly insulted and called derogatory names like this ‘albino thing’ and “monkey’.”* (Participant#7).

The terms used to refer to people with albinism have been cited in research by Braathen and Ingstad (2006: 606), whereby locals use terms such as “mzungu,” which refers to a European or white man, and “napwere,” which refers to a “pea-brownish” colour when they speak about or call people with albinism. Similarly, in Mali, people with albinism are referred to as “gombè,” meaning “red man,” due to their sunburned complexion (Imperato & Imperato, 2006). Additionally, the names “Zeru Zeru” (‘ghost-like creature’), “mzungu” (‘white man’), and “shawa” (‘monkey’) are also terms and labels used for people with albinism in eastern and southern Africa, particularly Zimbabwe, Tanzania, South Africa, Malawi, and Mozambique.

Another participant articulated their perspective on labelling in the context of HIV-seropositive infections and albinism: *“This thing of calling us persons with albinism. We*

*do not like it. We were born with albinism we did not get it because we were doing wrong things. Look at HIV and AIDS, few are born with HIV, but most get infected for many of their own reasons. Unlike us we had no choice in albinism we were born like this".* (Participant#10).

Although participants in this study objected to being called *albinos* some studies still refer to people with albinism as *albinos*. One such study is that of Adediran (2015) entitled: *We thought we will be safe here: Narratives of Tanzanian Albinos in Kenya and South-Africa*. Ironically, this study articulates Kenyan and South African people with albinism voices on abuse. Similarly, within media broadcasts it is common to see labels such as: *The tragic story of Tanzanian Albinos – hunted for body parts for witchcraft* (Zmescience, 2021); *Zimbabwe: Ostracized albinos describe life as hell on earth* (AP News, 2016) and *DR Congo albinos live in fear* (Africa News, 2016).

Other participants went on further to express that people with HIV/AIDS (PWHA) purposely got infected, chose not to take antiretroviral drugs and got grants to assist them manage their lives. One participant highlighted that the similarity between HIV and albinism involved a sexual act, one being pregnancy and the other at a time pregnancy as well, but mostly due to risky sexual practices. Studies have highlighted that risky and unprotected sex is the primary mode for HIV infections (Oladepo & Fayemi, 2011; Wilson & Saithiyasusuman, 2015).

The labelling and comparison between albinism and HIV did not end there, as other participants compared albinism to Covid-19, highlighted the global attention that the latter receives from the mass media, government, humanitarian organisations. In addition, the emphasis and encouragement for all global citizens to get vaccinated with this global outcry not occurring to the exact proportion for albinism and people with albinism (Reiter, Pennell, & Katz, 2020).

*"Now if our lives are not bad enough, there is Covid. So much fuss about a disease that started in China. We are people with albinism, we getting killed left right and centre*

*there not so much noise about us but a disease that started two years ago everyone is shouting. There's a vaccine for Covid, how come there's no vaccine for albinism. Even HIV there so much money for it where the money for albinism?"*

(Participant#5)

*"I am sure people who had Covid-19 do not get called names, instead people celebrate them or feel sorry for them. Every day on television we hear how many infections, how many deaths. But what about us people with albinism are born, abused and die without all this hullabaloo. Treat us all equal, no matter what the sickness is."* (Participant#3).

### **5.2.8.2 Emotional, Physical and Sexual Abuse**

It was critical to ask a follow-up question to ascertain the types of abuse experienced by people with albinism in the society in which they live as the opening questions asked of them revealed that all participants had experienced abuse. Participants expressed that they had been subjected to sexual abuse. In terms of the sexual abuse experienced by participants, these findings corroborated with Uromi's (2014) study and Women's Perspectives on News (2011), regarding sexual aggression in terms of rape being a human rights violation, yet many women with albinism (WWA) living in Africa are raped and violated due to albinism being viewed as a cure for HIV/AIDS.

This was evident when two participants from the semi-structured interviews indicated the follows:

*"I was repeatedly battered, psychologically tortured, and raped."* (Participant#14)

Though, three female participants reported they had experienced sexual abuse, none volunteered whether they knew if the sexual violations were HIV-related as reported in several studies in that having sex with a WWA is considered a cure for the disease.

*"I have been emotionally and physically abused, as well as subjected to discrimination."* (Participant#10)

### **5.2.8.3 Fear**

The study confirmed that people with albinism are fearful as a result of maltreatment imposed on their lives. According to Ojedokun (2018), people living with albinism are no longer able to live regular lives due to the continual dread of being assaulted, humiliated, trafficked, or murdered. As a result of communal mistreatment, they claimed to have had a series of ritualistic murders that compelled those with albinism to seek police protection and sanctuary in locations deemed safe. This got proven when two of the participants in the semi-structured interviews expressed his/her dissatisfaction with the following:

*“I am scared of walking in public with pride, scared of walking in the streets freely.”*  
(Participant#2)

*“The abuse that I have experienced and witnessed has badly affected my life. My rights of movement and freedom have been affected, I am always at risk, I can’t enjoy my life to the fullest because I am now fearful.”* (Participant#16)

Similarly, scholars such as Mswela (2013) have discovered that persons with albinism live in terror of being hunted and killed for their body parts, a worry that is shared by many other researchers. Ero (2021) also stated that attacks, threats, killings, abductions, possession of body parts, and the exhumation of graves of people with albinism have caused trauma to family members who have witnessed their relatives' dismembered bodies in some communities in Africa. The literature findings suggest that people with albinism and their family members live in terror of their life. They fear for their life as a result of the notion that they lack rights that protect them from assault and murder (Mswela, 2017).

### **5.2.9 Causes of abuse and brutal killings of people living with albinism**

This section of the analysis discusses a number of themes and sub-themes that relate to abuse of brutal killings of people with albinism in KZN.

### **5.2.9.1 Factors Contributing to the Abuse and Brutal Killing of people with albinism in Kwazulu-Natal**

The participants in this study were asked to identify the factors that contributed to the maltreatment and murder of people who have albinism because of their race or ethnicity. Participants had a lot to say in this topic, even though they reacted with a variety of different justifications for their positions. This section of the study has identified several themes that are related to the contributory elements that lead to the abuse and cruel killing of people with disabilities (people with albinism). They are discussed in the following ways:

### **5.2.9.2 Lack of Awareness and Inadequate Knowledge on Albinism and people with albinism**

The study found that the public lacks awareness and had inadequate knowledge about people with albinism, and as result, they abuse and abduct them. Shivaraiashankara et al. (2002) also affirmed that public education and awareness is lacking and it remains central to changing their negative minds regarding the abuse and attacks on people with albinism.

Two participants said that:

*“People lack awareness about Albinism.”* (Participant#20)

*“People do not understand the condition as a result they tend to create their own explanation as to what albinism is, and how people who have the condition should be treated. Some others think that once we come closer to them, they will get infected by the disease.”* (Participant#26)

### **5.2.9.3 Fear**

The outcomes of the study revealed that when the general population sees a person

with albinism, they tend to look down on them because they do not have a thorough understanding of albinism and people with albinism. Since they regarded people with albinisms as social outcasts who constituted a threat to society, they opted to torture, traffic, or murder them in their quest to shed light on the mystery surrounding them. These findings concurred with the Ecological Systems Theory where KirstAshman (2010:12) stated that it is utmost imperative for an individual to have a sound understanding of the "person-in-the environment". Hosking (2008:14) has similar feelings, stating that people with albinism are considered as "deficient, pitiable, wicked or malicious, dangerous or worthless" regardless of their cultural background. Basing their arguments on Hosking (2008), the participants believed that they are perceived as outcasts by the general public.

One member made the following statement to emphasise the preceding argument:

*"They are afraid of us thinking that they will be contaminated with our disease."*

(Participant#3)

Another participant stressed,

*"The public think that we are just outcast and not human beings as they are."*

(Participant#21)

The study verified that people with albinism are fearful as a result of maltreatment imposed on them. According to Ojedokun (2018), people living with albinism are no longer able to live regular lives due to the continual dread of being assaulted, humiliated, trafficked, or murdered. As a result of communal mistreatment, they are claimed to have had a series of ritualistic murders that compelled those with albinism to seek police protection and sanctuary in locations deemed safe.

This was demonstrated when one of the participants in the semi-structured interviews expressed his/her dissatisfaction with the following:

*"I am scared of walking in public with pride, scared of walking in the streets freely."*

(Participant#1)

One participant articulated, *"The abuse that I have experienced and witnessed has*

*badly affected my life. My rights of movement and freedom have been affected, I am always at risk, I cannot enjoy my life to the fullest because I am now fearful.”* (Participant#5)

Similarly, scholars including Mswela (2017), have discovered that persons with albinism live in terror of being hunted and killed for their body parts, a worry that is shared by many other researchers. Ero (2021) also stated that attacks, threats, killings, abductions, possession of body parts, and the exhumation of graves of people with albinism have caused trauma to family members who have witnessed their relatives' dismembered bodies in some communities in Africa.

#### **5.2.9.4 Cultural Beliefs and Practices**

The outcomes of the investigation in this area revealed startling statements made by the general public and directed at people with albinism. The outcomes of the study, for example, revealed that the general public believes that a person with albinism's body parts form a mixture (*muthi*) that has extraordinary qualities. In support of the study's findings, Mtetwa (2010) stated that around governmental elections, the number of people with albinism murders increases because some people believe that their bodies contain mystical, magical, and supernatural powers that can positively sway elections or re-elections in favour of specific politicians. Furthermore, some people believe that albinism people's organs are sources of good fortune targeted at improving their lives and well-being (Mswela, 2017).

A participant remarked, *“I think is because of the myths and untrue beliefs that the body parts of people with albinism makes good concoctions (muthi).”* (Participant#6) Another remark uttered by one participant, *“The public has strong cultural beliefs, myths and a lot of false stories about the special powers that our body parts hold that it can even bring luck to them”.* (Participant#25)

#### **5.2.9.5 Business Opportunity, Enrichment and Luck**

The study's findings also revealed public remarks, such as the claim that an albino person's body parts can make one wealthy. This suggests that albinism-related body parts can be used to lift people out of poverty and into prosperity. The study findings concurred with Cruz-Inigo, Ladizinski and Sethi (2011), whose study found that in Africa, people with albinism, including women, children, men and the aged, are hunted for their body parts (hair, limbs and heads) as the sale of these body parts is a lucrative business, and also for the mining and fishing industries. This is because the mining and fishing sectors profit from the selling of body parts. Traditional witchdoctors use people with albinism body parts to produce charms and magical potions and killing people with albinism and harvesting their body parts is a lucrative industry (Pillay, 2013). Based on Pillay's (2013) findings, two participants said that:

*"It is the ideology that when you have killed a person living with albinism and sell his or her body organs, you become rich."* (Participant#11)

Another participant stated, *"The corrupt public has a belief that our body parts have a magic of making a person who has been living in poverty to become wealthy because we attract riches."* (Participant#18)

According to Makulilo (2011), there is a widespread notion that a person with albinism's bodily parts have magical qualities that can bring wealth. The use of albino people's body parts as charms is popular in places such as Tanzania and South Africa. These charms, which include albino women's breasts and fingers, albino men's genitals and legs, as well as albino blood, are believed to bring fortune (NOAH, 2005).

#### **5.2.9.6 Medicine and Healing**

In some African countries, sexual relations with a woman with albinism (WWA) are believed to be useful in healing HIV and AIDS (Uromi, 2014; Women's Perspectives on News, 2011). According to the participants', women and young girls are raped by the public, particularly men who believe that sleeping with and having sexual relations with someone who has albinism can cure the illness.

According to *Participant #8*, "You know what, if you rape an albino woman, you will be healed of HIV/AIDS."

*Participant#12* stated, "The public believes that if HIV-positive males sleep with and have sexual relations with women who have albinism, HIV/AIDS will just vanish."

According to the United Nations Committee on the Elimination of Discrimination Against Women (2015), it is alleged that when men have sexual contact with women who have albinism, the HIV/AIDS virus is promptly healed.

### **5.2.10 Negative impact of abuse**

This was another study objective, which required participants to share personal accounts of how the abuse and murder of people with albinism has impacted their lives. Numerous themes arose as a result of the responses of participants. They are discussed as follows:

#### **5.2.10.1 Fearful and Feeling Unsafe**

The study findings showed that people with albinisms' lives have been affected negatively by being fearful and feeling unsafe in the communities in which they reside. According to Ojedokun (2018), people living with albinism are no longer able to live regular lives due to the continual dread of being assaulted, humiliated, trafficked, or murdered.

In supporting the argument by the author above, a participant articulated: "*I am afraid of everyone and that's a challenge because my brothers and sisters are being killed on a daily basis.*" (Participant #4)

One participant remarked that, "*I am affected negatively; I am no longer like a normal human being. It is like I am an animal that people harvest to feed themselves.*" (Participant #13)

One participant stated, "*I do not trust even my parents because people make a lot of*

*money through us.” (Participant #4)*

### **5.2.10.2 Diminishing Self-Esteem**

According to the findings of the study, people with albinism sometimes feel as though their self-esteem is eroding as a result of the abuse they receive from the general public.

Participant#10 said, *"It has had a detrimental impact on me since I am constantly afraid and have lost my self-confidence."*

According to a Human Rights Watch Interview (2017), people with albinism are perpetually depressed and have low self-esteem as a result of the harassment they receive from the general public.

### **5.2.10.3 Relationships**

According to the study findings, some women with albinism prefer to be without a partner rather than to be in a relationship. The study findings corroborated those of Benyah (2017), who observed that a lot of women with albinism prefer to live alone owing to self – and public stigma, and many feel compelled to live alone or in seclusion. According to Cruz-Inigo, Ladizinski and Sethi (2011), people with albinism have disconnected themselves from anything conducted by societies and they feel unsafe from members of the communities in which they live.

This became evident as two participants stated, *"...as a woman I am not involved in a relationship."* (Participant #15)

Another participant said, *"I will never get married and even be involved in any relationship."* (Participant #22)

#### **5.2.10.4 Psycho-Social**

According to the findings of the study, the people with albinism might occasionally suffer emotional and psychological consequences as a result of the abuse that the general public heaps upon them.

This was confirmed by one participant who stated, *“I am affected emotionally and psychologically because of the abuse that public impose on us.”* (Participant #17)

Waugh (2005) also revealed that external social forces have an emotional and psychological impact on those with albinism. Machipisa (2002) noted in another study that people with albinism are emotionally impacted throughout their lives as a result of the difficulties and disappointments they face.

#### **5.2.10.5 Recluse and Anti-Social Behaviour**

The study discovered that people with albinism avoid social interactions and even go outside freely due to their perceived risk from the public. Ero (2021) expressed a similar sentiment, arguing that attacks, threats, killings, abductions, possession of body parts, and exhumation of graves of people with albinism have caused trauma to family members who have witnessed their relatives' dismembered bodies in some African communities.

One participants highlighted that, *“I prefer to live a life of indoors and I no-longer go to town or even to a shop because maybe I am already sold.”* (Participant #20)

One participant made the following comment: *“I am badly affected by the notion we are the sacrifice of other human beings. My rights of movement and freedom have been affected, I am always at risk, I can't enjoy my life to the fullest.”* (Participant #25)

A study by Mswela (2017) also discovered that persons with albinism are living a fearful life as a result of maltreatment imposed on their lives. According to Ojedokun (2018), people living with albinism are no longer able to live regular lives due to the continual

dread of being assaulted, humiliated, trafficked, or murdered.

### **5.2.6 Coping strategies of people with albinism**

The study explored how victims of abuse cope (psychologically, emotionally, and financially) with the trauma of the abuse they witnessed or read about. This question was significant because it was intended to determine whether participants were resilient to the abuse. Surprisingly, this question elicited a wide range of responses from the participants. The following were some of the coping strategies people with albinism receive:

#### **5.2.11 Support from Family Members**

The study discovered that some individuals with albinism receive help from family members in order to manage psychologically and emotionally after experiencing or witnessing public mistreatment. The findings of the study agreed with the National Organisation for Albinism Hypopigmentation (NOAH), (2021) in that families and close friends of people with albinism normally play a very significant role in bringing up self-esteem and encouragement for them to come out of self-denial. This means that families find it crucial to easily discuss problems that they face in society.

Two participants attested to this by stating, *“I normally get support from my family and those close to me to ensure that are not affected but able to cope.”* (Participant # 14) and

*“My parents are always there for me when going through trauma.”*(Participant # 19)

The foregoing comments are consistent with those expressed by the National Organisation for Albinism Hypopigmentation (NOAH), (2021), which also stated that parents, as close family members of abuse victims, play a critical role in counselling them through fear and stress. Additionally, the organisation emphasised how critical it is for victims' family members to connect with their sentiments and express them through play, running, or crying — whatever physical outlet helped relieve the emotion. The literature and findings indicated that counselling, as well as the victim's response

to the advice, validates and releases the victim's inner strength during the healing process.

### **5.2.12 Self-Motivation**

It has been found that some people with albinism engage in self-motivation from time to time in order to avoid being traumatised by the negative consequences of maltreatment placed on them. The National Organisation for Albinism Hypopigmentation (NOAH), (2021) indicated that victims of abuse should learn to deal with the situation by understanding human nature and that behaviour of some people is negative, which is one of the first steps in learning to deal with these experiences as an individual.

This was supported by several participants, who stated, *“I always motivate myself even though thoughts keep running in my head.”* (Participant #2) *“I am self-motivated to continue to live in the same community and I try to understand the situation. However, it is not easy and that’s a fact.”* (Participant #23)

*“In life, I have learnt to cope with things and accept them as they are even though it takes a lot emotionally and psychologically.”* (Participant #26)

Brown’s (2010) study concurred with the study findings that self-motivation is the greatest approach to deal with public insults and slurs. The author stressed that the greatest way to overcome poor self-esteem is by self-motivation and family support, which can help create self-confidence and dignity.

### **5.2.13 Supported by Teachers**

According to the findings of the study, some persons with albinism can cope emotionally and psychologically because they had received assistance from their teachers after they had been mistreated or observed their loved ones being abused themselves. The findings of the study agreed with Baker (2018), who found in her study

that teachers play a tremendously significant role in the lives of people with albinism as they assist them to grow, learn and realise their full potential in life.

One participant stated the following in support of the aforementioned point of view, *“At school, I used to talk to my teacher about everything that was going on in my life and around me, she really helped me cope.”* (Participant #24)

According to Baker (2018), educators as a whole play a crucial role in raising self-esteem among learners who are abused by encouraging them to be self-sufficient and believe in themselves and that they have the same potential as others.

#### **5.2.14 South African Social Security Agency (SASSA) Grant**

The study's findings indicated that some people with albinism receive assistance from SASSA in the form of a stipend that assists them financially, because they believe that the public perceives them as prey, to solve their problems. According to Nebre (2018), people with albinism are unemployed and this has led to not having income and national governments in well-established countries support their citizens with small grants to sustain them.

One participant emphasised, *“Financially, I am always waiting for the social grant because I cannot work with people who see me as a prey, and I cannot go to public. I am really afraid to mix with any person.”* (Participant #9)

#### **5.2.15 Difficult to Cope**

Despite the fact that some participants said they could cope because of the many forms of assistance they received from family, friends, and organisations, the researcher also found that some people with albinism had a hard time adjusting. The study noticed with worry that participants felt this way for a variety of reasons. The findings of the study corroborated the findings of Mswela (2017), who stated that people with albinism are unable to deal with the abuse they suffered on their own since it was beyond their

ability.

The following is how many participants expressed it, *“I am not well sir to be honest. You can’t easily cope in this situation. Each and every year we get the cases of people living with albinism being killed.”* (Participant #4)

*“The situation is tricky, it is not easy to cope, you never know who to trust and you always question people’s true intentions about you.”* (Participant #18)

*“Coping is too far sir and financial I don’t think we will make it since I have lost hope in this society.”* (Participant #23)

#### **5.2.16 Intervention strategies for combating abuse and prevent the abuse and brutal killings of people with albinism in Kwazulu-Natal**

For the study it was critical to elucidate the current intervention techniques in place to address the people with albinism-related abuse and murder. In this regard, participants were invited to provide their personal thoughts on an open-ended topic regarding the intervention options of which they were aware. According to the participants' findings, intervention mechanisms were in place to address situations of the abuse and murder of people with albinism. The following are the suggestions used to manage the situation:

##### **5.2.16.1 Law Enforcement**

According to the study's findings, law enforcement is in place to ensure that those responsible for imposing abuse and murder on people with albinism are apprehended. The study revealed that once convicted, criminals were imprisoned for a period of time. According to the United Nations (2013), law is enforced for the criminalisation of abuse against people with albinism and if culprits are not known, their investigation and the prosecution is severely executed to ensure that they are imprisoned. To substantiate the preceding sentiments, several participants demonstrated with the following comments:

*“It is consoling that anyone who abuses us is jailed even though such people come out*

*of jail after few years.” (Participant #3)*

*“The law enforcement is working with the community to help fight against those who are excited in abusing and killing us.” (Participant #13)*

According to Nkrumah (2019), African countries should take steps to guarantee that all perpetrators of abuse against persons with albinism are apprehended and prosecuted in order to ensure that the general public is aware that abuse against individuals with albinism is prohibited by international law. Baker et al. (2021) went on to say that law enforcement is essential in assuring the protection of people with albinism who are victims of abuse by members of the community who have a negative attitude toward them.

#### **5.2.16.2 Albinism Foundation**

According to the findings of the study, persons who have albinism have an albinism foundation, which is responsible for receiving all complaints and ensuring that people who have albinism are living in peaceable circumstances. The findings of the study agreed with those of Mswela (2017), who claimed that the albinism society is critical in ensuring that incidences of mistreatment of persons with albinism are reported and that appropriate legal action is taken by the authorities.

Two participants stated the following in support of the aforementioned sentiments:

*“We have organisations like Masiqoqane Albinism foundation that were established by certain individuals to help people with albinism. These organisations are for people with albinism to report any case of abuse or murder.” (Participant #11) and*

*“I know of Masiqoqane Albinism foundation whose sole purpose is to educate people in our country about albinism.” (Participant #15)*

### **5.2.16.3 Awareness Campaigns**

According to the findings of the study, one of the intervention options is the deployment of public awareness campaigns. This means that activities to raise knowledge about albinism should be carried out to ensure that people with albinism are treated on an equal basis with everyone else in society. The International Albinism Awareness Day by the United Nations General Assembly (2015) also emphasised that awareness campaigns should be used to express concerns at the attacks against people with albinism, including their children.

Two participants stated the following in support of the aforementioned sentiments:

*“Even though in countries like Zambia, Tanzania etc. they moved all people with albinism into one shelter, in RSA we only have awareness campaigns. This campaign is sometimes on Ukhozi FM.” (Participant #14) and*

*“Currently, I only know the awareness campaign as a strategy in South Africa. This campaign is responsible for educating the public about our condition and that we are human beings like any other person.” (Participant #19)*

The study findings corroborated with Mswala (2016), who stated that raising awareness campaigns are necessary to provide substantial education aimed at behaviour change to address society's lack of knowledge and to dispel widespread myths that being albino is a curse and that the body parts of individuals with albinism could bring wealth.

### **5.2.16.4 Use of Media**

The study revealed that the province of KwaZulu-Natal is using media to ensure that the public is educated and becomes aware of the wrong acts of the abusing and killing

of people with albinism. The Ecological Systems Theory also emphasises that the environment in which people are abused need to be identified and changed for good to enable the victims to live in a conducive and humanly comfortable area, other than living as prey to a lion (Kirst-Ashman, 2010:12).

One participant said, *“Teaching local citizens on radio and television.”* (Participant #25)

The findings of the study concurred with Burker, Kaijane and John-Langba (2014) whose study findings indicated that media reports of violence against people with albinism have raised awareness and mostly focused on identifying and punishing the perpetrators. Franklin et al. (2018) further mentioned that media attention has also raised awareness of the need to address the challenges facing people with albinism, including stigma and the lack of access to education directed to the public.

### **5.2.17 The debate over the effectiveness of intervention strategies**

The participants were asked if they thought the intervention tactics were adequate in terms of preventing the abuse and murdering of people with albinism. The study findings found that the intervention strategies were not enough to convince and make the people with albinism feel safe in KwaZulu-Natal Province. Some of the arguments against sufficiency include the following:

#### **5.2.17.1 Insufficiency of Intervention Strategies**

According to the findings of the study, the intervention strategies were insufficient in their effectiveness.

This was mirrored by two participants, *“The intervention strategies are not enough because people with albinism are still being abused and victimized on a daily basis due to the ignorance of people.”* (Participant #4) and

*“Not really, a lot of work still needs to be done especially in rural areas where these things mostly occur. There is no coverage that educate people about prohibition of abuse of people with albinism.”* (Participant #26)

According to Franklin et al. (2018:2), people with albinism in African cultures perceive their circumstances as unfriendly, mainly because of the ineffectiveness of institutional and national initiatives. In other words, intervention efforts are believed to be inadequately designed to address the abuse directed against people with albinisms. Poverty, insufficient access to medical treatment, a lack of favourable learning environments and services, a lack of community empowerment, a lack of participation in community events, discrimination and stigma all have had an impact on the well-being of persons with albinism in Africa (Nyamu, 2020).

#### **5.2.17.2 Lack of Consistent Awareness Campaigns**

The study revealed that there is lack of consistent awareness campaigns that will cover the whole of South Africa. According to Ero, Muscati, Boulanger and India (2021), national governments worldwide are not pushing enough in making the public aware of the rights of people with albinism. In fact, all citizens need to be aware of the rights and freedom of people with albinism.

This was showed by several participants as follows:

*“No Sir, the problem with this country of ours is that awareness campaigns are done only if there are cases of abuse. It should be done at least every month”* (Participant #23)

*“No, not everyone gets an invite to some of these awareness campaigns and the law seems to be very weak because a culprit is jailed only few months and after that the person is out. What is that really?”* Participant #6)

*“Not enough, because these criminals are in rural communities.”* (Participant #21)

#### **5.2.1.1 Law Enforcement Very Weak**

The findings of the investigation indicated that law enforcement is extremely underfunded, and that the perpetrators will never stop abusing and murdering persons

with albinism. Ero, Muscati, Boulanger, and India (2021), and Franklin et al. (2018) corroborated the study findings by demonstrating that national governments' law enforcement is ineffective because of the rapid release of criminals. The authors noted that criminals are not held in prison until they have served their whole sentence but are released before they have completely absolved themselves of their wrongdoings.

One of the participants provided the following statement in support of the aforementioned statement, *“Not really, the law is very weak. You can’t kill a person and after 6 months in jail you are out. What’s that?”* (Participant #1)

### **5.2.17.3 Lack of Policy**

The study established that people with albinism felt that there is lack of policy that covers or protects their lives. The study showed that all other people have their policy in place however, for people with albinism there is none.

One participant said, *“There is no policy that covers us as people with albinism.”* (Participant #9) Another participant voiced, *“Not really, we do not have a policy that protect us. Women and children have their policies on abuse. Why do they have to do the same to us?”* (Participant #17)

Several authors such as Franklin et al. (2018) have claimed that Africa lacks a robust policy to safeguard persons with albinism from the abuse that is imposed upon them in their daily lives. Mswela (2017) went on to suggest that the public takes advantage of persons with albinism by abusing and murdering them. She cited the fact that the rules in existence do not adequately protect people with albinism and do not set out how perpetrators of abuse will be punished as justification.

#### **5.2.17.4 Poor Leadership in the Country**

The study's findings suggested that South Africa had ineffective leadership, as the issue of abuse and murder of persons with albinism is not adequately addressed by the government.

Participants attested to this by stating, *“No, we lack leadership in our country. Others are protected while we are left to struggle on our own.”* (Participant #5)

*“A real president cannot keep quiet when his people are abused and murdered. This thing is political. We don’t have leadership in our country, and this is like we are strangers in our own land.”* (Participant #21)

The above findings corroborated Burke, Kaijage and John-Langba (2014) findings that some government nationals maybe be trying to assist people with albinism, however, there are still issues such as not doing enough to protect the people with albinism. Additionally, there is poor support from leadership of national governments for people who are victims who do not have a voice.

#### **5.2.17.5 Poor Addressing of Public**

During the study, the participating people with albinism stated that the issue of abuse is not adequately addressed in the manner in which it should be. The findings indicated that the issue of albinism-related abuse and murder is cannot help if it is only directed to people with albinism, but it has to be directed to the perpetrators. A study conducted by Pooe-Moneymore (2012) also revealed that the public is not fully educated in that people with albinism are also human beings who are disabled.

This scenario was exemplified when one participant with albinism stated, *“The whole thing is confusing, it looks like when they address the issue of abuse against us, they are talking to us. What’s that? They should talk to the citizens because these people are heartless. Traditional healers who use body parts of animals and people should be*

*stopped from operating that way. They are the ones doing this. They must be screened period.” (Participant #16)*

### **5.2.18 Recommendations to develop intervention strategies to address the abuse and brutal killing of people with albinism in Kwazulu-Natal**

The study asked participants to spell out contextual solutions that needed to be adapted to enhance and improve current intervention strategies to reduce and eliminate the abuse of people with albinism. The following are recommendations from the participants:

#### **5.2.18.1 Intervention by Government**

The findings of the study revealed that the government must become completely involved in the subject of the abuse and murdering of persons who have albinism in the country, which is a topic of urgent importance.

This was confirmed by two participants, who stated what they had observed:

*“The government must intervene and assists because they look more relaxed, yet we are being killed and abused. Government cannot keep quiet at a time like this. She must intervene or else they will finish us in no time.” (Participant #17)*

*“The government must intervene. I never heard the president of our country addressing this issue. What is the problem?” (Participant #20)*

The preceding excerpt concurs with the United Nations General Assembly Security Council (2013) which states countries should take steps and invest resources in initiating legal action against perpetrators of attacks against people with albinism, public condemnation of such attacks, temporary shelter for people with albinism who are threatened with attack, and public awareness raising campaigns.

### **5.2.18.2 Educating People about Albinism**

The participants recommended that there is an urgent need to educate the public about albinism - in general it is just a disease like any other illness. This means that the public needs to know this instead of seeing people with albinism as their prey. Some of the participants made the following recommendations:

*“People need to be educated more about people living with albinism, more and more communities need to be educated especially the older generation because it is them who perpetuate false beliefs to the younger generation.”* (Participant #15)

*“A wide range of educational talks on the topic needs to be done, the campaigns and initiatives need to educate the public that we are also human beings just like them.”* (Participant #19)

*“If the public could be educated about albinism, they can also respect us as human beings. However, if government is still quiet, they cannot take it serious.”* (Participant #23)

The recommendations above concurred with the United Nations Human Rights Council Advisory Committee (2014) which highlighted that lack of educating the public on abuse against people with albinism is missing in many countries, especially in Africa. The United Nations (2020) continued to point out that the manner in which discrimination is faced by persons with albinism is as a result of lack of education of the public.

### **5.2.18.3 Equal Treatment**

The findings of the study revealed that people with albinism believe that they do not receive equal treatment like other people with disability. As a result, they recommended that they need to be treated equally with all other human beings on a pressing basis, immediately.

According to one participant, *“It is hard to say. The only thing needed is for everyone to restrain from inhuman thoughts and learn to treat us the way they want to be treated.”* (Participant #13)

The United Nations (2020) had call for the global community to respect people with albinism because they are also human beings. The information and literature discussed revealed the need for all global citizens to fight discrimination against and murder of people with albinism and work towards a world free of discrimination, fear, violence and stigma.

#### **5.2.18.4 Awareness Campaigns**

The participants recommended an urgent need for awareness campaigns that will cover the abuse and murdering of people with albinism. According to the findings, the awareness campaigns are meant to educate the public about albinism as a condition or sickness. Two participants who were very vocal said:

*“It would be of great help if awareness campaigns were done all over the country but must be very intensive in rural areas, as people there are unaware of the condition.”* (Participant #1)

*“Campaigns on awareness of abuse and killings of people with albinisms must be done on radios and television on monthly basis. Educating traditional healers that we have body parts like them.”* (Participant #7)

In support of the study's findings, the United Nations General Assembly (2015) stressed the urgent need for awareness programmes aimed at educating society about the dangers of discrimination, abuse and murder of people with albinism. According to the United Nations General Assembly (2015), the campaign was also intended to encourage Member States to continue their efforts to protect and preserve the rights of albinism to life, dignity and security, as well as their right not to be subjected to torture or cruel, inhuman or degrading treatment or punishment, and to ensure equal access to employment, education, justice, and enjoyment of life. According to Cruz-Inigo, Ladizinski and Sethi (2011), national governments had numerous awareness

campaigns dedicated to reducing albinism discrimination. These campaigns have been organised to ensure that the public is made aware that abuse against people with albinism is illegal.

#### **5.2.18.5 Policies Protecting People with Albinism**

The study's findings recommended an urgent need of a policy protecting people with albinism in the country. The study findings demonstrated that people with albinism there is a need for the intervention of government in ensuring that there is a policy in place that protects people with albinism from the public especially culprits who abuse and kill people with albinism. As a result, they advocated for the immediate creation of a legislation that protects them against public abuse and murder.

As one participant put it, “We need a written policy that protects us just like in countries Namibia, Zambia and Tanzania”. This abuse and murdering of people with albinism would come to an end if such is implemented.” (Participant #14)

According to the 1948 Universal Declaration of Human Rights, there shall be no person kept in slavery or servitude; slavery and the slave trade shall be abolished in all their manifestations. This indicated that no one should be regarded as a slave, as all human beings are equal regardless of their origins or skin colour. It is self-evident that people have the right to freedom of movement and residence within the borders of each state and not treated as slaves. They have the right to leave and return to any country, including their own (Universal Declaration of Human Rights, 1948).

#### **5.2.18.6 Imprisonment of Perpetrators**

The participants recommended that there is an urgent need for perpetrators of abuse and killings against people with albinism to face life sentence in prison if convicted of murdering persons with albinism on purpose. One participant also said:

*“People who are found guilty of abuse and killings of people with albinism should be*

*jailed for life (udilika jele). This can end myth that our body parts are a solution for their wealth.” (Participant #12)*

According to the European Parliament (2018), all African government authorities must take proactive measures against any criminal organisation or individual engaged in witchcraft or human trafficking, provide adequate training and resources to police, thoroughly investigate albinism-related crimes, end impunity, and seek urgent international assistance to conduct impartial and effective investigations into all reported attacks against people with albinisms.

#### **5.2.18.7 Ban Traditional Healers Using Body Parts**

The participants also recommended that there is a need to prohibit all traditional healers from using human and animal body parts to treat public health problems. The participants further mentioned that traditional healers who abuse and murder people with albinism should never be regarded as community doctors because of their unacceptable acts. A violator of other citizens' rights, particularly those of the disabled, is subject to the death sentence, according to the Universal Declaration of Human Rights (1948), which ensures that all citizens are safeguarded from such abuses. Traditional healers who use the body parts of people with albinism in rituals, according to Baker (2018), should be detained and barred from practising as traditional doctors in any capacity.

One participant demonstrated this by stating, *“Everyone should have access to information about albinism. The government should deal with traditional healers who use body parts to treat problems of people. We are not supposed to be killed in order to cure someone’s problem. In reality, these traditional healers deserve to be in custody.”* (Participant #7)

#### **5.2.19 Professional bodies providing counselling**

Again, the study felt it was important to ask all participants if they had received any counselling after being abused and what kind of counselling they had received. This

question elicited many responses from the participants. The following is an account of their responses:

#### **5.2.19.1 Social Workers Provide Emotional Counselling**

It was found that after experiencing abuse or witnessing abuse in the lives of their loved ones, people with albinism were found to be receiving emotional counselling from professional social workers, according to the findings of the study.

This was demonstrated by two individuals, who stated, *“I got emotional counselling from a social worker.”* (Participant #13)

*“I received counselling from the hospital where a social worker was invited to address my emotions which were uncontrollable.”* (Participant #23)

The study findings corroborated with the International Federation of Social Workers (2014) that social workers are professionals whose responsibility is to promote social justice, human rights, collective responsibility and respect for diversities of all human beings. They engage people, communities and structures to address individual's challenges with the aim of improving upon their well-being irrespective of health status, race, creed, religion, age, gender and sexuality.

#### **5.2.19.2 Psychologist Provide Psychological Counselling**

It was found that after experiencing abuse or witnessing abuse in the lives of their loved ones, people with albinism were found to be receiving psychological counselling from professional psychologists, according to the findings of the study. The International Federation of Social Workers (2014) also revealed that social workers, together with psychologists, are considered to be professionals, whose responsibility is to provide counselling to ensure that they deal with the root cause of the problem.

This was shown by some people with albinism who stated, *“A social worker who was dealing with case invited a psychologist to deal with my psychology because I was really traumatised.”* (Participant #10)

*“Psychologists play a crucial role in counselling us as we are unable to cope emotionally and psychologically especially after you have been abused or witnessed the abuse of our brothers and sisters. We become traumatized emotionally and psychologically.”* (Participant #21)

### **5.2.19.3 Albinism Society and Support Groups**

The study discovered that after experiencing abuse or witnessing abuse in the lives of their loved ones, people with albinism were found to be receiving psychological and emotional counselling from the albinism society. The findings of the study agreed with those of Mswela (2017), who claimed that the albinism society is critical in ensuring that incidences of mistreatment of persons with albinism are reported and that appropriate legal action is taken by the authorities.

This was shown by one person with albinism who indicated, *“We have albinism society, and it is very helpful in case we experience trauma. For example, I received psychological counselling from the Albinism society for many times.”* (Participant #5)

### **5.2.20 Type of Counselling Received**

As a follow-up question, the study felt it was essential to ask all participants the kind of counselling they received from those people or professional bodies specialising in counselling. This question drew quite several debates from the people with albinism. What follows are the sub-themes that emanated from the participants.

#### **5.2.20.1 Trauma Counselling**

According to the findings of the study, some people with albinism who had been abused or seen abuse were received trauma counselling from the professionals who

specialised in counselling.

In emphasising the statement above, Participant 17 said, *“I have received traumatic counselling from social workers to ensure that I become normal after experiencing abuse”*.

The findings of the study were in line with NASW (2008), which revealed that social workers are professionals dealing with cases of mental problems to ensure that victims become normal after encountering a traumatic experience.

#### **5.2.20.2 Emotional and Psychological Counselling**

The study also established that after people with albinism had experienced abuse or witnessed abuse, they received emotional counselling from the professionals specialising in counselling.

Participant 12 articulated, *“I have received emotional counselling from social workers after my encounter with abuse from my fellow citizens”*.

Participant 14 said, *“I have been helped by social workers and psychologist to receive psychological counselling because what I saw knocked me down. You can't enjoy life knowing that you can be murdered at any time. This is traumatic experience”*.

The South African Mental Health Care Act (17 of 2002 section 1: xvii) also stated that social workers and psychologists must provide mental healthcare for people with psychological problems to ensure that they are fully supported.

#### **5.2.20.3 Helpfulness of counselling received**

Again, all participants were asked if the counselling they received was beneficial to their lives. This was intended to collect information on how the counselling aided them. This question sparked discussions among the participants, and their responses were recorded as follows:

## **Coping Well**

According to the findings of the study, some people with albinism who had been abused or seen abuse were able to manage effectively with their condition if they receive counselling from professionals. The profession of social work addresses cases of victims of abuse in a society to ensure that counselling is provided to eliminate stress and mental disorders (NASW, 2008).

Three participants demonstrated this by stating the following:

*“The counselling I received was really helpful, even though you cannot be at peace knowing that anything can happen”.* (Participant #9)

*“It helped me cope psychologically and emotionally, but it cannot change the situation.”* (Participant #13)

*“I coped from psychological, emotional and emotional stress however, the situation has not changed.”* (Participant #17)

The findings above corroborated the Ecology Systems Theory “whereby the terminology of adaptation is highly applied and regarded as the ability to adjust to the new conditions” whilst coping means “a form of human adaptation where an individual tries to overcome problems encountered (Zastrow & Kirst-Ashman, 2013:30).

## **Unable to Cope**

The study also found that there were people with albinism who indicated that even though they received psychological and emotional counselling, they were unable to cope. The findings of the study corroborated the findings of Mswela (2017), who stated that people with albinism are unable to deal with the abuse that they suffer on their own since it is beyond their ability.

This was emphasised by one participant who said, *“Even though I have received counselling emotionally and psychologically, it is not easy to cope. I can be murdered anytime. This problem is still existing.”* (Participant #2).

## **5.2.21 Intervention strategies to combat the abuse and killing of people with albinism**

Another study question sought to discuss relevant strategies for combating the abuse and killing, as well as the trafficking of people with albinism. It should be noted that this question elicited detailed information from the participants, as well as a large number of responses and comments. The following table summarises these responses:

### **5.2.21.1 Self-Defence Classes**

The study established that some people with albinism felt that they needed a training to be able to defend themselves in case they face an attempt of abuse and murder by the public.

One participant articulated, *“We must have self-defence classes where we will be trained to defend ourselves whenever we are being attacked. We need the involvement of law because without the law we will be abused.”* (Participant #5)

### **5.2.21.2 Awareness Campaign**

The study findings revealed that there is an urgent need for awareness campaigns that will cover the abuse and murdering of people with albinism. According to the findings, the awareness campaigns were meant to educate the public about albinism as a condition or sickness. Mwsela (2016) supported the study findings by indicating that awareness and educational campaigns were required to bring an end to superstitious beliefs, discrimination and stigma that people with albinism’s body parts can solve many problems in a life of an individual.

This became evident when two participants who said, *“More awareness is required, and we also need a constitution. We need our own representative in parliament. I believe this can make the public aware.”* (Participant #3) *“Awareness must not be done on only on certain occasions, it should be done regularly.”* (Participant #10)

The findings above corroborated the United Nations General Assembly's International Albinism Awareness Day (2015), which emphasised the importance of awareness campaigns in numerous parts of the world, aimed at sensitising people to the human rights situation of people with albinism, which has remained limited, and recognising the critical importance of increasing awareness and understanding of albinism to combat global discrimination and stigma against people with albinism.

### **5.2.21.3 Amend the Constitution**

The study's findings suggested that persons with albinism voiced concern about the country's absence of a policy or constitution protecting all individuals with albinism. As a result, they advocated for the immediate creation of a legislation that protects them against public abuse and murder. Section 11 of the South African Constitution recognises the right of all citizens to life and was chronicled in the *Carmichele* case that stated that entities and people are obliged to refrain from infringing on citizens' right to life. The right to life errs on the protection of all citizens through processes, laws and agencies facilitating and providing such protection (The Constitution of the Republic of South Africa, 1996).

As participants stated,

*"People with albinism must be protected because they also have the right to live just like gays".*

(Participant #15)

*"We need our own constitution and this urgent."* (Participant #19)

According to the 1948 Universal Declaration of Human Rights, there shall be no person kept in slavery or servitude; slavery and the slave trade shall be abolished in all their manifestations. This indicates that no one should be regarded as a slave, as all human beings are equal, regardless of their origins or skin colour. It is self-evident that people have the right to freedom of movement and residence within the borders of each state

and they are not treated as slaves. The European Parliament (2018) concurred with the above findings, emphasising that the primary responsibility of a state is to implement the human right to social security in order to protect all citizens, including vulnerable groups, and to ensure that all national governments in areas where abuse and murder of people are prevalent, such as the issue of people living with albinism, ensure effective protections for people with albinism in order to uphold their right to life and liberty.

#### **5.2.21.4 Involving Government**

The findings of the study revealed that the government must become completely involved in the subject of abuse and murdering of persons who have albinism in the country, which is a topic of urgent importance.

This was demonstrated by one participant, who stated, *“Government must be involved. We need justice and strategies to protect us.”* (Participant #13)

The European Parliament (2018) concurred with the above findings, emphasising that the primary responsibility of a state is to implement the human right to social security in order to protect all citizens, including vulnerable groups, and to ensure that all national governments in areas where the abuse and murder of people are prevalent, such as the issue of people living with albinism, ensure effective protection for people with albinism in order to uphold their right to life and liberty.

#### **5.2.21.5 Educating the Public About Albinism**

It was found that there is an urgent need to educate the public about albinism in general - it is just a disease, like any other illness. This means that the public needs to know this to not see people with albinism as their prey. According to the United Nations Human Rights Council Advisory Committee (2014), a lack of education of the public about the abuse against people with albinism is missing in many countries, especially in Africa. The United Nations (2020) continues to point out that the manner in which

discrimination faced by persons with albinism is as a result of lack of education of the public.

One person with albinism also mentioned that, *“The public need strong education about albinism because they think we are not human beings. They must know that albinism is a condition that can affect anyone at any time.”* (Participant #1)

#### **5.2.21.6 Equal Rights for people with albinism**

According to the findings of the study, people with albinism believe that they do not receive equal treatment as those who do not have albinism. As a result, they demanded that they be treated equally with all other human beings on a pressing basis, that is immediately. Unfair discrimination is a violation of people’s right to equality as enshrined in the South African Constitution (South African Human Rights Commission, 2017). The right to equality facilitates the equality of all citizens irrespective of their gender, sex, race, religion, political affiliations, opinions, health, disabilities to ensure citizens enjoy their fundamental rights and freedom.

According to one participant, *“Women and children have their own rights, what about us. Political parties must discuss our problems just like any other case.”* (Participant #18)

The study's findings were consistent with the Universal Declaration of Human Rights (UDHR) (1948), which affirmed that all individuals in this world have the right to dignity and the equal and inalienable rights of all members of the human family as a foundation for global freedom, justice, and peace.

#### **5.2.21.7 Ban Traditional Healers Using Human Body Parts**

The study's findings indicated that people with albinism perceived a need to prohibit all traditional healers from using human and animal body parts to treat public health problems. The data established that such traditional healers should never be regarded

as community doctors because of their unacceptable behaviour in the society.

Two participants revealed that, *“We need to come up with a strategy that will teach people about albinism, especially about cultural beliefs that are false. Traditional healers using body parts of human beings must be banned. They are very evil.”* (Participant #6)

*“Remove traditional healers believing that human body parts can bring wealth to any person. They deserve to be jailed.”* (Participant #12)

The study's findings concurred with those of the European Parliament (2018), which stated that all African government authorities must take a proactive stance against any criminal organisation or individual engaged in witchcraft or human trafficking by providing adequate training and resources to police, thoroughly investigating albinism-related crimes, putting an end to impunity, and urgently seeking international assistance to conduct impartial and effective investigations.

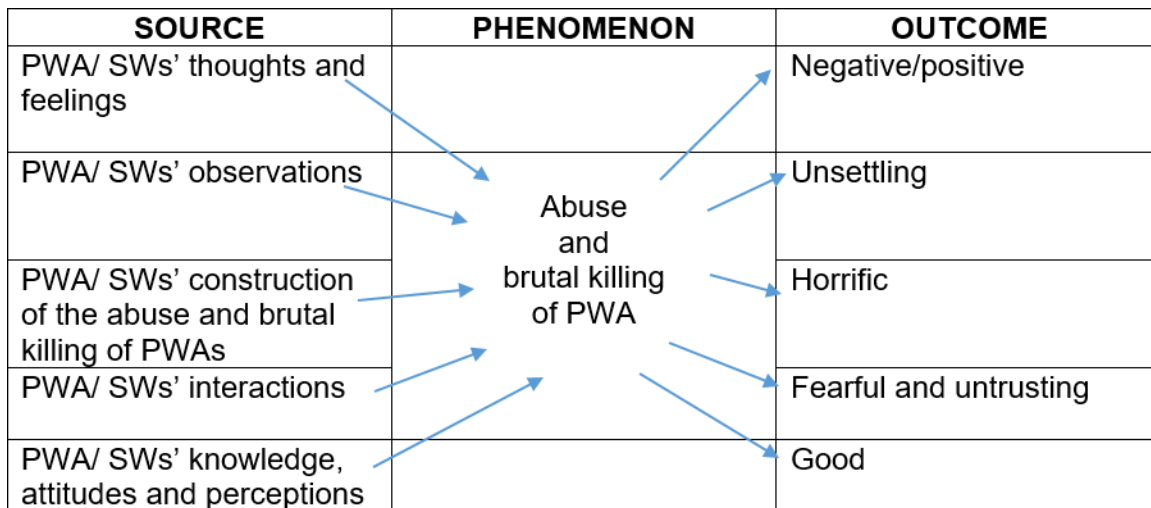
## MAIN THEMES

<ul style="list-style-type: none"> <li>1. <u>Main theme</u>: Causes of abuse and brutal killing of people living with albinism</li> <li>1.1. Level of awareness and abuse of PWA</li> <li>1.2. Personal experience with abuse</li> <li>2. Negative impact of abuse</li> <li>2.1 Fearful and feeling unsafe</li> <li>2.2 Diminishing self-esteem</li> <li>2.3 Relationships</li> <li>2.4 Psycho-social</li> <li>2.5 Recluse-anti-social</li> <li>3. Coping strategies of PWA</li> <li>3.1 Support from family members</li> <li>3.2 Self-motivation</li> <li>3.3 Supported by teachers</li> <li>3.4 SASSA grant</li> <li>4.6 Intervention strategies for combating abuse and killings of PWA</li> <li>4.1 Law enforcement</li> <li>4.2 Albinism society or foundation</li> <li>4.3 Awareness campaigns</li> <li>4.4 Use of media</li> <li>5. The debate over the effectiveness of intervention strategies</li> <li>5.1 Insufficiency of intervention strategies</li> <li>5.2 Lack of consistent awareness campaigns</li> </ul>	<ul style="list-style-type: none"> <li>5.3 Law enforcement very weak</li> <li>5.3 Lack of policy</li> <li>5.4 Poor leadership in the country</li> <li>5.5 Poor addressing of public</li> <li>6. Solution to improve intervention strategies</li> <li>6.1 Intervention by government</li> <li>6.2 Educating people about albinism</li> <li>6.3 Equal treatment</li> <li>6.4 Awareness campaigns</li> <li>6.5 Policy that protects people with albinism</li> <li>6.6 Jail culprit</li> <li>6.7 Ban traditional healers using body parts</li> <li>7. Professional bodies providing counselling</li> <li>7.1 Social workers provide emotional counselling</li> <li>7.2 Psychologists provide psychological counselling</li> <li>7.3 Albinism society</li> <li>8. Helpfulness of counselling received</li> <li>8.1 Coping well</li> <li>9. Relevant strategies to combat the abuse and killings of PWA</li> <li>9.1 Self-defence classes</li> <li>9.2 Awareness campaign</li> <li>9.3 Constitution for people with albinism</li> <li>9.4 Involving of government</li> <li>9.5 Educating the public about albinism</li> </ul>
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**Figure 5-1: Themes originating from the data collected**

### 5.2.22 Participants 'matrix (PM)

The data gathering process and the study findings facilitated the creation of a Participants' (People with albinism and Social Workers) Matrix, which reflects participants' thoughts, feelings, emotions, constructions, interactions, knowledge, attitudes and behaviour regarding the brutal killing and abuse of people with albinism and their perceptions of interventional strategies.



**Figure 5-2: Participants' Matrix**

The Participants' Matrix synergises the data collection sources and the findings and presents an easy outline for the gatekeepers, social workers and researchers to understand people with albinism thoughts, feelings, observations, constructions of the abuse and killings, interactions and knowledge, attitudes and perceptions of the phenomenon. The matrix highlights the importance of understanding people with albinism and the impact thereof on them.

### 5.3 PART TWO: DATA ANALYSES RELATED TO SOCIAL WORKERS

#### 5.3.1 PARTICIPANTS DEMOGRAPHIC DATA (SOCIAL WORKERS)

Participants were required to respond to structured questions relating to personal information such as their gender, age, educational level and number of years working.

**Table 5-4: Representation of Demographic Profile**

Variable	eThekweni Metropolitan Municipality: n=5		uMgungundlovu District Municipality: n=5		TOTAL n=10
	Female	Male	Female	Male	TOTAL
<b>Gender</b>	4	1	3	2	10
<b>Age</b>	<b>Female</b>	<b>Male</b>	<b>Female</b>	<b>Male</b>	<b>Total</b>
• 41-50	1	0	1	1	3
• 18-30	0	0	0	0	0
31-40	3	1	2	1	7
Older than 50	0	0	0	0	0
Total	4	1	3	2	10
<b>Education Level</b>	<b>Female</b>	<b>Male</b>	<b>Female</b>	<b>Male</b>	<b>Total</b>
BA Social Work	3	1	3	1	8
Masters in Social Work	1	0	0	1	2
Total	4	1	3	2	10
<b>Duration participants have lived in KZN</b>	<b>Female</b>	<b>Male</b>	<b>Female</b>	<b>Male</b>	<b>Total</b>
24 months and less	0	0	0	0	0
2 - 5 years	2	0	2	1	5
6 - 10 years	1	1	0	1	3
11 and above	1	0	1	0	2
Total	4	1	3	2	10

##### 5.3.1.1 Gender

The results in Table 5.2 illustrate that four of the females were based in eThekweni Metropolitan and three other females were in the uMgungundlovu district municipality. Moreover, one male was from eThekweni Metropolitan and two other males from the uMgungundlovu district municipality.

### **5.3.1.2 Distribution of the Respondents by Age**

The majority (7) of social workers who participated in the study were in the age group 31-40 years, while two of the social workers were between the ages of 41-50 years.

### **5.3.1.3 Educational Level of Participants**

The table above shows that eight of the participants had a BA in Social Work while two had a master's in social work. The findings in terms of level of education showed that social workers have a qualification to perform the duties of counselling.

### **5.3.1.4 Work Experience**

The majority of the social workers (five) reported that they have worked between two and five years and there only three who have worked six to ten 6 - 10 years. Finally, only two had worked 11 or more.

## **5.3.2 Causes of abuse and brutal killings of people living with albinism**

This section of the analysis discusses a number of themes and sub-themes that relate to the abuse and brutal killings of people with albinism. It is critical to highlight that before delving into the causes of abuse and cruel killings of persons with albinism, it was necessary for this study to ascertain the extent to which people with albinism are aware of the abuse.

### **5.3.2.1 Types of Abuse Experienced by People with Albinism**

It was important in this study to determine the type of abuse experienced by people with albinism. The study showed that the social workers were of the view that people with albinism are discriminated against and called by different names to ensure that they inflicted with pain.

The study findings corroborated with Brocco (2015) and Murray (2015), who also discovered that people with albinism are subjected to discriminatory and derogatory

labels and names because of their features, resulting in stereotypes being given to them.

A participant responded, *“They are discriminated, and they are called names like Whiteman (umlungu).”* (Social Worker #3)

A study by Hosking (2008) also stated that language is a potent tool for shaping beliefs and realities. As such, language can be dehumanising through taunting and name-calling.

### **5.3.2.2 Emotional Abuse**

The study findings from social workers demonstrated people with albinism are subjected to a great deal of abuse whereby their fellow citizens abuse them emotionally and psychologically.

One participant said, *“People with albinism are usually abused emotional and even psychological by their fellow citizens.”* (Social Worker #6)

The study findings were in-line with Waugh’s (2005) findings which discovered external social forces have an emotional and psychological impact on those with albinism. Machipisa (2002) noted, in another study, that people with albinism are emotionally impacted throughout their lives as a result of the difficulties and disappointments they face.

### **5.3.2.3 Rape as an Abuse**

It was also discovered that social workers were aware of cases in which people with albinism are repeatedly raped by their fellow citizens as a result of cultural beliefs. The study findings supported Uromi (2014) and Women's Perspectives on News (2011) that people with albinism, especially women, experience sexual aggression in the form of rape, which is a violation of human rights.

This was emphasised by one participant, *“A number of cases of serious rape by fellow citizens have come to my attention, and I have spoken with the victims. Unfortunately, cultural ideas are frequently the root cause of rape.”* (Social Worker #1)

### **5.3.3 Contributing factors to the abuse and killing of people with albinism**

This portion of the chapter examines the causes that contribute to the abuse and killing of people with albinism. It also includes a list of themes. It was observed that this purpose elicited a great deal of emphasis from the responders, which resulted in the development of various themes. The following points were raised throughout the discussion:

#### **5.3.3.1 Cultural Beliefs and Practices**

The results of the study showed that social workers believed that people with albinism are abused by the public because the public has a strong belief that a person with albinism's body parts form a concoction (*muthi*) that has extraordinary qualities to promote one's life. In support of the study's findings, Mtetwa (2010) stated that around governmental elections, the number of people with albinism murders increases because some people believe that their bodies contain mystical, magical, and supernatural powers that can positively sway elections or re-elections in favour of specific politicians. Mswela (2017) also stated that some people believe that albinism people's organs are sources of good fortune, targeted at improving their lives and well-being.

Two participants said, *“Our patients always tell us that the public has a belief that their body parts are very good at making a concoction (muthi).”* (Social Worker #9)

*“We always hear stories that the public has strong cultural beliefs that using an eye of a person with albinism can make one promoted at work.”* (Social Worker #5)

### **5.3.3.2 Poor of Knowledge on Albinism and people with albinism**

According to the findings of the study, the social workers revealed that the general public was unaware of, and has an insufficient understanding, about persons with albinism, and as a result, they abuse and abduct them. The findings from the social workers concurred with Shivaraiashankara et al. (2002) whose findings also affirmed that public education and awareness was lacking and it remained central to changing their negative minds regarding the abuse and attack towards people with albinism.

This became apparent when participants expressed dissatisfaction with the following: *“I think a big problem here is lack of awareness about Albinism. People do not know what it means to be infected and being a person with albinism.”* (Social Worker #7) and *“People do not have any knowledge at about albinism and to them they see a prey if a person has albinism.”* (Social Worker #10)

### **5.3.3.3 Body Parts for Medicinal and Healing**

According to Uromi (2014), sexual relations and using the body parts of a person with albinism are widely believed to be useful in healing HIV/AIDS and their body parts for making strong concoctions for healing ailments. According to the Women's Perspectives on News (2011), the claims of having sexual intercourse with a woman or a young girl who has albinism can cure many disorders including HIV/AIDS are not supported. The findings from social workers concurred with the above statements that using body parts of a person with albinism heal many problems including HIV/AIDS.

This was emphasized by two participants:

*“I have heard many reports that some use the body parts of people sleep with people with albinism to be healed from HIV/AIDS.”* (Social Worker #1) *“There is a strong belief from our people that having a sexual intercourse with a person with albinism heals anyone who has contaminated HIV/AIDS.”* (Social Worker #7)

According to the United Nations Committee on the Elimination of Discrimination

Against Women (2015), the public has a strong perception that when men have sexual contact with women who have albinism, the HIV/AIDS virus is promptly healed.

#### **5.3.3.4 Prosperity and Wealth**

The findings of the study revealed that the body parts of people with albinism make people rich. This view was supported by Cruz-Inigo, Ladizinski and Sethi (2011) whose findings also showed it was believed that some body parts of people with albinism bring wealth to people. It has been argued that in Africa, people with albinism, including women, children, men and the aged, are hunted for their body parts (hair, limbs and heads) as the sale of these body parts is a lucrative business, including the mining and fishing industries. This is because the mining and fishing sectors profit from the selling of body parts. Traditional witchdoctors use people with albinism body parts to produce charms and magical potions and killing them and harvesting their body parts is a lucrative industry (Pillay, 2013).

Two participants revealed that, *“I heard many times from people with albinism that we counsel that the public believes that their body parts bring luck and can make one rich.”* (Social Worker #4)

*“We are hearing from the public and newspapers that the body parts of people with albinism attract riches and wealth and that is the reason they are hunted day and night.”* (Social Worker #9)

Many people believe that parts of people with albinisms' bodies are magical and can bring prosperity, according to Makulilo (2011). In countries like Tanzania and South Africa, albino people's body parts are used as charms. Albino breasts, fingers, genitals, and legs, as well as albino blood, are some of the most popular lucky charms (NOAH, 2005).

### **5.3.4 Reporting cases of abuse to social workers**

The study wanted to ascertain how victims of abuse reported cases of abuse to the social work department. Having said that, the social workers were asked to reveal if their patients who had been victims of abuse had reported cases of abuse. The feedback from the social workers revealed numerous ways in which cases of abuse were reported. The following were some of the subthemes emanated from the findings.

#### **5.3.4.1 Report through Police-Station**

According to social worker responses, some victims of albinism reported incidences of abuse to police departments. A study by United Nations (2020) also indicated that when there were cases of abuse and murder of people with albinism, police were able to follow-up information received about the culprits who were arrested.

This was reiterated by some respondents *in many cases, some victims of abuse are brought to us by police officers to provide counselling to the victims.*" (Social Worker #3) and

*"Some people with albinism report cases of abuse to SAPS and at times we are invited to provide counselling to the victims of abuse."* (Social Worker #8)

The study findings are in-line with United Nations (2020) who also reported that cases of abuse are reported made to those in authority for law enforcement to play its role in handling those who mistreat and kill people with albinism.

#### **5.3.4.2 Report through Neighbours and Family Members**

The findings also showed that people with albinism who were victims of abuse, had reported cases of abuse to their neighbours and family members. The findings of the study agreed with the National Organisation for Albinism Hypopigmentation (NOAH), (2021) that neighbours and families, as well as friends of people with albinism normally reported cases of abuse to the respective police stations and social work development.

This means that neighbours, family members and friends take it upon themselves to ensure that cases of abuse against people with albinism are reported and addressed.

Social workers stated, *“It is quite distressing that people with albinism are subjected to such harsh treatment by their fellow countrymen. We occasionally receive such information from their neighbours and family members that they are going through tough times”*. (Social Worker #1).

Another participant said, *“Sometimes we see such cases when we are doing social behaviour change programmes and some are reported by community members.”* (Social Worker #6)

### **5.3.5 Steps taken to address the matter**

According to the study, it was vital to interview social workers about the necessary procedures they take when people with albinism had reported cases of being abused. There were multiple responses to this topic, which were then grouped together to form themes. The following are the responses, which were organised into topics, as described by the researchers:

#### **5.3.5.1 Provision of Counselling**

According to the survey, social workers were helping people with albinism by providing counselling when they had experienced or witnessed their brothers and sisters being abused by the public. The Theory of the Ecological System also emphasised that social workers are expected to play a pivotal role in understanding their clients' problems and help solve their mental and psychological problems (Kirst-Ashman, 2010:11). The study findings corroborated with the International Federation of Social Workers (2014) in that social workers are professionals whose responsibility is to promote social justice, human rights, collective responsibility and respect for diversities of all human beings. They engage people, communities and structures to address individual's challenges with the aim of improving upon their well-being irrespective of health status, race, creed, religion, age, gender and sexuality.

This was demonstrated by participants who indicated, *“It is our duty as social workers to provide counselling to people with albinism who are traumatised by the public.”* (Social Worker #2)

Another social worker stated, *“I provide psychological counselling to the victims of abuse and also empower them to stand on their own”.* (Social Worker #3)

The findings of the study concurred with Coleman’s (2018) research findings that people with albinism at times feel rejected by society and are always emotionally traumatised and for these two reasons, it is important that they are provided counselling to establish their self-esteem and confidence.

### **5.3.6 Type of counselling provided to people with albinism**

The study wished to discover what type(s) of counselling social workers provided to people with albinism who were victims of community abuse. This was an important question since it was used to determine whether or not counselling was delivered and what kind of counselling was supplied. Surprisingly, the participants responded in a variety of ways to this topic. Some of the advice that was given was as follows:

#### **5.3.6.1 Emotional Counselling**

The study findings established that people with albinism who were emotionally abused would receive counselling from professional social workers. The findings corroborated those of Mswela (2017), who stated that people with albinism cannot be in a position to cope with the abuse they experience, they need emotional counselling to be able to overcome the syndrome they are faced with.

This was demonstrated by two participants, who stated the following:

*“I normally do counselling to people with albinism who are referred to us from the police-station and community.”* (Social Worker #7) and

*“I provide counselling that is related to stress when people with albinism are unable to cope on their own.” (Social Worker #1)*

The findings of the study agreed with the International Federation of Social Workers (2014) that the profession of social workers is to ensure support to all individuals with emotional counselling, which is a service of the society. These findings also corroborated Richardson (2002) in the Resilience Theory which is applied to a person who has been bombarded by daily stress, abuse, or trauma caused by a particular scene whereby the person was disrupted in his/her internal and external sense of balance, presenting challenges, as well as opportunities.

#### **5.3.6.2 Provision of Psychological Counselling**

The findings of the study discovered that after people with albinism had experienced or witnessed abuse in the lives of their loved ones, they receive psychological counselling from professional social workers to ensure they bounced back to normal life. The International Federation of Social Workers (2014) also revealed that social workers, together with psychologists, are considered as professionals, whose responsibility is to provide counselling to ensure that they deal with the root cause of the problem.

This was evidenced by a social worker who articulated, *“As a social worker, at times I do psychological counselling to people with albinism who have been abused or witnessed a traumatic abuse.” (Social Worker #4)*

#### **5.3.6.3 Trauma and Debriefing Counselling**

The study discovered that social workers provide trauma and debriefing counselling to people with albinism who had experienced or witnessed abuse in their lives. The Resilience Theory showed that counselling a victim of abuse is crucial in ensuring that he/she adapts physically, mentally and spiritually in order to bounce back to normal

senses (Richardson, 2002).

One social worker went on to say, *“I always go all out to ensure that when cases of abuse are narrated by the victims, you find that they are traumatised and they require trauma and debriefing counselling.”* (Social Worker #10)

The International Federation of Social Workers (2014) also revealed that social workers, together with psychologists, are considered as professionals, whose responsibility is to provide traumatic counselling to ensure that they deal with a root cause of the problem.

### **5.3.7 Interventional strategies in place**

It was important to identify interventional strategies that are in place to ensure that cases of abuse of people with albinism are addressed speedily and eliminated. This question brought very insightful debate from social work professionals. Themes were formulated as follows:

#### **5.3.7.1 Awareness Campaign**

According to the findings of the study, the social workers were putting in much effort in ensuring that there is an awareness campaign regarding abuse and killing of people with albinism. This means that social workers are making the community of South Africa aware that abusing and killing people with albinism is not necessary as they are human beings like everyone. Mwsela (2016) supported the study findings by indicating that awareness and educational campaigns are required to bring an end to superstitious beliefs, discrimination and stigma that people with albinism's body parts can solve many problems in a life of an individual.

Two participants said:

*“We sometimes do awareness campaigns in schools and in the communities where the abuse of people with albinism is very high.”* (Social Worker #1) *“Our radio station always talks about such cases. I mean that Ukhozi FM talks about cases of abuse.”* (Social Worker #5)

The findings above corroborated the United Nations General Assembly's International Albinism Awareness Day (2015), which emphasised the importance of awareness campaigns in numerous parts of the world, aimed at sensitizing people to the human rights situation of people with albinism, which has remained limited; and recognizing the critical importance of increasing awareness and the understanding of albinism in order to combat global discrimination and stigma against people with albinism.

#### **5.3.7.2 Visiting of Rural Areas to Raise Awareness**

According to the study's findings, social workers visit rural areas where the abuse and killing of people with albinism is rife to ensure that awareness is raised. According to Mswela (2017), visiting people in rural areas to raise awareness and deliver educational campaigns is vital to ensure that these people have enough information too about people with albinism.

To substantiate the preceding sentiments, one participant voiced, *“We as social workers take a stand against the abuse and killings of people with albinism by visiting rural communities to talk about the wrong acts of the community.”* (Social Worker #8)

#### **5.3.8 Law Enforcement**

The social workers raised the importance of the availability of law enforcement to ensure that those responsible for imposing abuse and murder on people with albinism are apprehended. This means that law enforcement ensures that criminals are imprisoned for a period of time, which demonstrates the sensitivity of the matter.

According to the European Parliament (2018), all African government authorities must take proactive measures against any criminal organisation or individual engaged in witchcraft or human trafficking, provide adequate training and resources to police, thoroughly investigate albinism-related crimes, end impunity, and seek urgent international assistance to conduct impartial and effective investigations into all reported attacks against people with albinism. To substantiate the preceding sentiments, a number of respondents stated the following:

*“We have law enforcement in place to where cases of abuse and killings of people with albinisms are reported. I have been a witness on that for several times.”* (Social Worker #4) and

*“The law enforcement is working together with us to ensure that all culprits are jailed to ensure that this barbaric act comes to an end.”* (Social Worker #10)

### **5.3.9 Service(s) needed for people living with albinism to ensure their safety**

Again, social workers were asked to point out services that they thought were urgently needed to ensure that people with albinism are safe in KwaZulu-Natal. This question raised several themes that are relevant to the current situation of people with albinism. The responses in this question were discussed as follows:

#### **5.3.9.1 Albinism Society**

The study recommended an urgent need of albinism society which will stand for all people with albinism in the province of KwaZulu-Natal. The findings of the study agreed with those of Mswela (2017), who claimed that the albinism society is critical in ensuring that incidences of mistreatment of persons with albinism are reported and that appropriate legal action is taken by the authorities.

This was supported by social workers who indicated, *“I am aware that people with albinism have their society to managed cases of abuse properly, the abuse and murder*

*of people with albinism would be a thing of the past.” (Social Worker #2)*

*“The albinism society must be funded by government in order to be managed properly and to ensure that it tackles all cases of abuse against people with albinism.” (Social Worker #6)*

### **5.3.9.2 There should be a Constitution for People with Albinism**

The social workers suggested that an urgent need for a policy or constitution of people with albinism to be drafted. The findings showed that the social workers encouraged the immediate implementation of a legislation that protects people with albinism against public abuse and murder.

Two participants put it as follows:

*“It is high time that government must protect people with albinism, and they must have their policy or constitution which protects them from the public.” (Social Worker #1) and “Without the involvement of and signing a document that protects people with albinism from the public, we will always have very frightening cases on the abuse of people with albinism. This need our government to stand up like they do for other genders and people who are gays.” (Social Worker #9)*

Several authors, namely Franklin et al. (2018), claimed that Africa lacks a robust policy to safeguard persons with albinism from the abuse that is imposed upon them in their daily lives. Mswela (2017) went on to suggest that the public is taking advantage of persons with albinism by abusing and murdering them. She cited the fact that the rules in existence do not adequately protect people with albinism and do not set out how perpetrators of abuse will be punished as justification.

### **5.3.9.3 South African Social Security Agency (SASSA) Grant**

The participating social workers revealed that there is an urgent need for a South African Social Security Agency (SASSA) grant, to assist people with albinism. This

means that people with albinism should receive a SASSA grant, as they fear socialising with the public. This grant could assist people with albinism who are not employed due to fear of the public who impose abuse on people with albinism. According to Nebre (2018), many people with albinism are unemployed and this has led to them not having an income. National governments of well- established countries should support their citizens with small grants to sustain them.

This become evident when two social workers articulated that, *“I think there is an urgent need for SASSA grant which should function as a financial service for people with albinism. Since they can’t socialise with the public because they fear that they will be slaughtered like animals, it is wise that they receive SASSA grant on monthly basis. It is based on I said that always refer them to relevant departments, where they can get all the essential services they need.”* (Social Worker #1) and *“I have referred many people with albinism to SASSA to get help financially as they are not employed for they fear to be abused and murdered by the public. So, government must take a stand and ensure that they receive the grant without any struggle.”* (Social Worker #3)

#### **5.3.9.4 Educating the Public about Albinism**

The study findings from social workers indicated an urgent need to educate the public about people with albinism - they are humans like any other person.

In emphasising the above findings, one social worker stated, *“As long as the public is not taught or educated about the public need strong education about albinism because they think we are not human beings. They must know that albinism is a condition that can affect anyone at any time.”* (Social Worker #2)

These findings agreed with the United Nations General Assembly (2015) document which emphasised a strong need to educate the public through awareness campaigns that the abuse and killing of people with albinism is discrimination and it is not acceptable in society.

### **5.3.10 Intervention strategies to combat the abuse and killings of people living with albinism**

According to the study's final question, social workers were expected to describe intervention measures that were appropriate to combating the abuse and killing of people who have albinism. Accordingly, the social workers were able to identify a number of measures that are extremely feasible to follow in order to ensure that the abuse and murder of people with albinism is completely eradicated from the world. The following tactics are discussed as themes in the following order:

#### **5.3.10.1 Strengthening of Awareness Campaign**

The findings of the study revealed that increased knowledge is needed to guarantee that local communities are fully aware of the wrongful mistreatment and murder perpetrated on those who have albinism, and that this awareness should be promoted. According to the findings, the purpose of the awareness campaigns is to educate the general population on how to accept and recognise persons who have albinism as well as their medical condition. In support of the study's findings, the United Nations General Assembly (2015) stressed the urgent need for awareness programs aimed at educating society about the dangers of discrimination, abuse and murder of people with albinism. This was demonstrated by two social workers, who stated the following:

*"I think it is very crucial for government and even our department as Social workers to raise more awareness on the wrongful act by our fellow south Africans that mistreating and killing people albinism is not accepted and tolerated."* (Social Worker #4) and  
*"Awareness on abuse and killings of people with albinism should be done on monthly basis to ensure that it is sensitise to people. The other very important aspect of awareness is government have awareness day for people with albinism. I believe this can play a pivotal role in the lives of the people with albinism and the public at large."* (Social Worker #7)

According to the United Nations General Assembly (2015), there is an urgent need for awareness campaigns to be reinforced to ensure that everyone in the society is fully

informed that people with albinism deserve respect and dignity like any other human person.

### **5.3.10.2 Constitution for People with Albinism**

It has been revealed that a constitution or policy protecting people with albinism from being mistreated or killed by the general public is urgently required. It is considered that a constitution or policy can place a stamp on the wrongfulness of mistreating and murdering persons who have albinism while also raising a powerful voice against it. As a result, they urged for the quick passage of legislation that would protect them from public abuse and murder, among other things. Section 11 of the South African Constitution recognises the right of all citizens to life and was chronicled in the *Carmichele* case that stated that entities and people are obliged to refrain from infringing on citizens right to life. The right to life errs on the protection of all citizens through processes, laws and agencies facilitating and providing such protection (The Constitution of the Republic of South Africa, 1996).

One social worker phrased it, *“It is time that a constitution or policy for people with albinism is put in place to ensure that these people are safe in their own country like us.”* (Social Worker #3)

Another social worker added. *“We as social workers need to push this agenda to government because we are dealing with these sensitive cases and without them getting support from us, I do not think they will make it. Let us drive the notion that their constitution is urgently needed.”* (Social Worker #6)

### **5.3.11 Albinism Society**

The findings of the study from social work demonstrated that it crucial that people with albinism have their own society which is responsible for all complains of people with albinism. The findings of the study agreed with those of Mswela (2017), who claimed that the albinism society is critical in ensuring that incidences of mistreatment of persons with albinism are reported and that appropriate legal action is taken by the

authorities.

This was proved by one social worker who said, "*I strongly believe that people with albinism need to have their own society which deals with their problems and take measure steps to government if need be.*" (Social Worker #10).

#### **5.4 CONCLUSION**

To conclude, the information acquired from people with albinism and social workers was examined and synthesised in this chapter. To guarantee that accurate and reliable data was acquired from the intended participants, the researcher began by familiarising the research assistant with the research questions. During fieldwork, the research assistant assisted with data collection by interviewing and taking notes. The transcribed findings from people with albinism and social workers were consistent with the fieldwork report. As a result of the analysed data, the study was unbiased and reliable. Finally, people with albinism agreed that intervention measures are critical in ensuring that all people with albinism, like any other citizen, are protected and safe in their country. In light of this, the study identified a number of intervention techniques that could be useful in addressing all of people with albinisms' difficulties. The summary, conclusions, and recommendations are presented in the next chapter.

## **CHAPTER 6: CONCLUSIONS AND RECOMMENDATIONS**

### **6.1 INTRODUCTION**

The previous chapter discussed the findings of the study which were combined together with the literature review and the theoretical framework. These three were discussed simultaneously in order to make accurate and reliable informed conclusions and recommendations. This study explored people with albinism and social workers' experiences, perspectives and perceptions of the abuse and brutal killing of people with albinism in two municipalities, eThekweni Metropolitan and uMgungundlovu District Municipality in the province of KZN. The participants' responses on their perspectives, observations, perceptions and experiences were in a quest to develop intervention strategies to address the abuse and brutal killing of people with albinism in KZN.

This study's findings will contribute to existing knowledge on the abuse and brutal killing of people with albinism in KZN, the factors that contribute to their human violations and atrocities and the ways in which intervention strategies can be developed. In this concluding chapter, the previous chapters in this thesis are summarised, an analysis of collected and transcribed data, and the themes originating from the data analysis discussed, as well as participants' recommendations for the development of intervention strategies to address the abuse and brutal killing of people with albinism in KZN that could facilitate a more inclusive, nurturing and improved environment for all people with albinism. The study deeply discussed the following chapters which formed part of the contribution to this chapter.

### **6.2 SUMMARY OF CHAPTERS**

**Chapter One**, an introductory background to the study and a rationale that motivated the pursuance of this topic, the primary aim, the objectives and research questions were discussed. In addition, summaries of the literature review, research methodology and theories underpinning this study were explored and discussed.

**Chapter Two** contained international, national and local reviewed literature pertaining to the topic under study. The chapter commenced with some historical, legislative and health context to people with albinism. The term albinism and people with albinism was defined. Sociological arguments were presented to unpack albinism and the stigmatisation and marginalisation, abuse and brutal murder of people with albinism. This is despite legislation and policies that aim to support people with albinism.

**Chapter Three** provided an in-depth presentation and discussion of the theories framing the study and supporting the findings. The use of the Ecological Systems Theory and Resilience Theory to underpin the study was relevant. The former theory facilitated an accurate and relevant lens to gain a comprehensive understanding of the types of abuse people with albinism are confronted with, the various systems available and their impact on people with albinisms in order to develop intervention strategies. In addition, the Resilience Theory (Masten, Best, & Garmezy, 1990) was relevant as it addresses: (a) individuals who have experienced traumatic events (abuse and killing of people with albinism) and have not recovered adequately therefrom; (b) individuals (people with albinism) who constitute high-risk populations but experience favourable outcomes; and (c) individuals who cope and adapt despite the stressors (abuse and murder of people with albinism) they experience in their lifetime (Masten, Best, & Garmezy, 1990).

**Chapter Four** presented a comprehensive overview of the research methodology, research design and research methods used in this phenomenological interpretivist qualitative study. The study sample of 26 people with albinism and social workers, who had two years and more experience counselling and dealing with people with albinism, participated in semi- structured face-to-face interviews and assisted in attaining rich data. In addition, a people with albinism as a research assistant facilitated acceptance with the study population and with observation during the interviews. The ethical considerations, trustworthiness and validity were also discussed in this chapter.

**Chapter Five** provided the analysis chapter whereby gathered data from people with albinism and social workers was unpacked and interrogated. This chapter focused on

participants' responses to the abuse and killing of people with albinism and how their perceptions, experiences, observations facilitated the development of intervention strategies to curb, reduce and eliminate all atrocities levelled at them. Such data could assist in a more supportive, inclusive environment in which people with albinism can live in harmony, devoid of fear, discrimination, stigma and murder. The use of interviews with open-ended interview guided facilitated- rich data being collected; such data was transcribed verbatim and IPA facilitated themes and subthemes.

**Chapter Six** the concluding chapter, provides an overview of all the chapters in this dissertation and summarises the key findings and utilises the participant's recommendations to develop intervention strategies to address the abuse and brutal killing of people with albinism in KwaZulu-Natal.

### **6.3 RESEARCH OBJECTIVES:**

- To explore the factors contributing to the abuse and brutal killing of people with albinism in KwaZulu-Natal.
- To investigate the coping strategies of people with albinism after hearing about, experiencing, witnessing or observing the abuse or killing of people with albinism.
- To explore the interventional strategies currently in place to combat or prevent the abuse and brutal killing of people with albinism in KwaZulu-Natal.
- To make recommendations to improve the strategies to combat the abuse and killings of people with albinism.

### **6.4 SUMMARY OF MAJOR FINDINGS**

The following section discusses the objectives along the findings of the as intended by the study from the beginning. The research objectives were turned into main themes of the study and subsequent sub-themes, which contributed to insightful findings.

#### **6.4.1 Factors Contributing to the Abuse and Brutal Killing of People with Albinism in Kwazulu-Natal**

Before establishing the causes of abuse and killing of people with albinism, the study had to find out from the people with albinism if they were aware of abuse and killing of people with albinism. Overwhelmingly, the study found that all people with albinism were aware of their abuse and killing in the country. The people with albinism further indicated that they once experienced abuse and witnessed their brothers and sisters being abused. The literature also demonstrated that people with albinism are mistreated in several countries worldwide (Franklin et al., 2018). The study findings also corroborated with Tambala-Kaliati, Adomako, and Kwabena Frimpong-Manso' (2021), who demonstrated in their study that people with albinism are subjected to brutal attacks in several African and European countries.

Concerning types of abuse once experienced by the participants, the study discovered that both people with albinism and social workers noted with concern that people with albinism are discriminated against because of their skin colour and they are labelled with different names.

In supporting the above statements, one person with albinism said, *"I have been labelled and discriminated against because of my skin colour. I am constantly insulted and called derogatory names like this albino thing and monkey"*.

While another person with albinism shared the same sentiments and said, *"They call me White man (umlungu), monkey and at times insulted me for no reason"*.

One social worker said, *"They are discriminated, and they are called names like Whiteman (umlungu)"*.

The literature also concurred with the study results whereby Brocco (2015) and Murray (2015) also reported in their studies that people with albinism are subjected to discriminatory and derogatory labels and names because of their features, resulting in stereotypes being given to them.

The study findings regarding people with albinism and social workers also discovered that other people with albinism were abused emotionally, physically and sexually.

One person with albinism said, *“I was emotionally and physically abused, as well as subjected to discrimination”*.

Another person with albinism voiced out that, *“I was repeatedly battered, psychologically tortured, and raped”*.

A social worker also said, *“A number of cases of serious rape by fellow citizens have come to my attention, and I have spoken with the victims. Unfortunately, cultural ideas are frequently the root cause of rape”*.

The literature also proved that people with albinism experience numerous forms of abuse from their fellow brothers and sisters. Uromi (2014) and Women's perspectives on news (2011) revealed that there is a belief that having sexual intercourse with a person with albinism can cure a person who is HIV positive.

Regarding factors contributing to the abuse and brutal killing of people with albinism, the study found that both people with albinism and social workers revealed that there are numerous factors contributing to the abuse and killing of people with albinism. One of the factors is lack of awareness and inadequate knowledge on albinism and people with albinism (PWA).

One of the people with albinism responded as follows, *“People don't understand the condition as a result they tend to create their own explanation as to what albinism is, and how people who have the condition should be treated. Some others think that once we come closer to them, they will get infected by the disease”*.

One social worker evidenced, *“I think a big problem here is lack of awareness about Albinism. People do not know what it means for a person to albinism”*.

The literature also affirmed that public education and awareness is lacking and it remains central to changing their negative minds regarding the abuse and attack towards people with albinism (Shivaraishankara et al., 2002).

Furthermore, the study showed that the public is fearful of people with albinism - to them, they are regarded as social outcasts who should not come closer to normal people because they might contaminate the disease.

One participant articulated, *"They are afraid of us thinking that they will be contaminated with our disease"*.

Another participant said, *"The public think that we are just outcast and not human beings as they are"*.

It was not surprising to discover that the literature also shared the same sentiments on this subject. Hence Hosking (2008:14) posited that people with albinism are considered as "deficient, pitiable, wicked or malicious, dangerous or worthless" regardless of their cultural background. Hosking (2008) further revealed that other people perceive people with albinism as outcasts and are not supposed to come closer to any normal person.

The study indicated that other contributing factors to the abuse and killing of people with albinism are cultural beliefs and practices. The study further showed that people with albinism and social workers were of the opinion that the general public has a strong belief that a person with albinism's body parts make a strong mixture (muthi) that has extraordinary qualities to heal and to bring fortune in one's life.

This was evidenced by one person with albinism who voiced, *"The public has strong cultural beliefs, myths and false stories about the special powers that our body parts possess. They always say that using our body parts will bring luck in their lives"*.

A social worker also said, *"Our patients always tell us that the public has a belief that their body parts are very good at making a concoction (muthi)"*.

A study by Mtetwa (2010) and Mswela (2017) also revealed that when it is time for governmental elections, the number of people with albinism murders increases because some people believe that their bodies contain mystical, magical, and supernatural powers that can positively sway elections or re-elections in favour of specific politicians.

The study also discovered both people with albinism and social workers stated that business opportunity, enrichment and luck were considered as other contributing factors that lead to the abuse and killings of people with albinism. The study showed that the body parts of a person with albinism are believed to be good at making any person wealthy. This suggested that it is believed the body parts of a person with albinism can make a person who is poverty stricken to be prosperous and rich.

In supporting the findings above, one of the people with albinism said, *“The corrupt public has a belief that our body parts have a magic of making a person who has been living in poverty to become wealthy because we attract riches”*.

One of the social workers also said, *“I heard many times from people with albinism that we counsel that the public believes that their body parts bring luck and can make one rich”*.

The literature that the study reviewed also pointed out that in Africa, people with albinism including women, children, men and the aged, are hunted for their body parts (hair, limbs and heads) as the sale of these body parts is a lucrative business, including for the mining and fishing industries (Cruz-Inigo, Ladizinski & Sethi, 2011). According to Makulilo (2011), some people have a strong belief that people with albinisms' body parts have magical qualities that can bring wealth over one's life.

It was also discovered that one major striking contribution towards the abuse and killing of people with albinism is the notion that their body parts can produce medicine and healing. The study findings from people with albinism and social workers proved that a large number of women are raped by men with HIV/AIDS since they believe that

having sexual intercourse with a person with albinism can cure anyone who is HIV positive.

One of the people with albinism reported on what they hear people say, "*You know what, if you rape an albino woman, you will be healed of HIV/AIDS*".

Another one remarked, "*The public has a belief that if HIV-positive person has sexual intercourse with a person with albinism, HIV/AIDS will just vanish*".

Uromi (2014) also revealed that some people from the public believe that having sexual intercourse with a woman or man with albinism (people with albinism) can heal anyone who is HIV/AIDS.

#### **6.4.2 Coping Strategies of People with Albinism after Hearing about, Experiencing, Witnessing or Observing the Abuse or Killing of people with albinism**

The study considered it crucial to start by asking people with albinism the negative impact of abuse in their lives. Hence the study discovered that people with albinism are living a fearful life and feeling unsafe due to the abuse and killing of people with albinism.

In support of the above, one participant remarked, "*I am affected negatively; I am no longer like a normal human being. It is like I am an animal that people harvest to feed themselves*".

Another participant said, "*I do not trust even my parents because people make a lot of money through us*".

The literature also indicated that people living with albinism are no longer able to live regular lives due to the continual dread of being assaulted, humiliated, trafficked and murdered (Ojedokun, 2018).

Another negative impact caused by the abuse and killing of people with albinism is that people with albinism have a diminishing self-esteem. The findings of the study

indicated that people with albinism sometimes feel as though their self-esteem is eroded as a result of the abuse they receive from the general public.

One participant said, "*Being abused and witnessing the abuse and killing of people with albinism has had a detrimental impact on me since I am constantly afraid and have lost my self-confidence*".

According to a Human Rights Watch Interview (2017), people with albinism are perpetually depressed and have low self-esteem as a result of the harassment they receive from the general public.

With regard to relationships and one of the negative impacts of abuse against people with albinism, the study indicated that women with albinism choose to be single rather than be in a relationship.

One of the participants uttered, "*I will never get married and even be involved in any relationship*".

The literature also indicated that many women with albinism prefer to live alone owing to self- and public stigma, and many feel compelled to live alone or in seclusion and exclusion due to abuse that they experience from the public (Benyah, 2017).

Concerning psycho-social, the study found that people with albinism sometimes suffer emotional and psychological consequences as a result of the abuse caused by their fellow citizens.

It became evident as one of the participants said, "*I am affected emotionally and psychologically because of the abuse that the public impose on us, and this is unbearable*".

According to Machipisa (2002), people with albinism are emotionally and psychologically impacted throughout their lives as a result of the difficulties and disappointments they face. The study also showed that people with albinism decided to be reclusive-anti-social due to the abuse that they experienced from the public.

One participant said, *“I prefer to live a life of indoors and I no-longer go to town or even to a shop because maybe I am already sold.”*

Another person with albinism made devastating remarks, *“I am badly affected by the notion we are the sacrifice of other human beings. My rights of movement and freedom have been affected, I am always at risk, I can’t enjoy my life to the fullest”.*

The literature also revealed that persons with albinism live a fearful life as a result of the maltreatment imposed on their lives (Mswela, 2013). According to Ojedokun (2018), people living with albinism are no longer able to live regular lives due to the continual dread of being assaulted, humiliated, trafficked, or murdered.

#### **6.4.2.1 Coping Strategies of people with albinism**

Having discussed the negative impacts caused by the abuse and killing of people with albinism, it became crucial for the study to reveal how people with albinism cope in such traumatic experiences. The study discovered that people with albinism have a very strong support from family members - some people with albinism are supported by their family members psychologically and emotionally after experiencing or witnessing public mistreatment.

One of the people with albinism said, *“I normally get support from my family and those close to me to ensure that I am not affected but able to cope”.*

According to the National Organisation for Albinism Hypopigmentation (NOAH), (2021), families and close friends of people with albinism normally play a very significant role in the bringing up self-esteem and encourage victims of abuse to come

out of self-denial. This means that families find it crucial to easily discuss problems that they face in the society.

Concerning self-motivation, the study found that some people with albinism motivate themselves to come out of trauma caused by abuse or witnessing their beloved ones being abused.

One participant said, *"I am self-motivated to continue to live in the same community and I try to understand the situation. However, it is not easy and that's a fact"*.

The literature also revealed that sometimes people with albinism practise self-motivation as a way of overcoming stress and mental problems associated with abuse or witnessing their loved ones experiencing abuse. The literature further clarified that the greatest weapon to overcome poor self-esteem is by self-motivation and family support, which can help create self-confidence and dignity (Anele, 2019).

Another coping strategy found to be effective in dealing with emotions and psychology is the support teachers give to people with albinism especially learners. The study indicated that some people with albinism are able to cope emotionally and psychologically because teachers give extra support in terms of counselling. The findings of the study agreed with Baker (2018), who in her study found that teachers play a tremendously significant role in the lives of people with albinism as they assist them grow, learn and realise their full potential in life.

Finally, the study showed that the SASSA grant played a very crucial role in the lives of people with albinism. It means that people with albinism receive SASSA grants in order to survive.

One of the participants remarked, *"Financially I am always waiting for the social grant because I cannot work with people who see me as a prey, and I cannot go to public. I am really afraid to mix with any person"*.

According to Nebre (2018), people with albinism are unemployed and this has led to not having an income; in well-established countries around the world, governments support their citizens with small grants to sustain them.

#### **6.4.2.2 Reporting Cases of Abuse to Social Workers**

The study showed that social workers were aware that people with albinism were reporting cases of abuse and killing to different authorities. The study indicated people with albinism report cases of abuse to the police station and to neighbours and families.

One social worker said, *“In many cases, some victims of abuse are brought to us by police officers to provide counselling to the victims”*.

The literature also showed that when cases of abuse and murder of people with albinism are reported, police are able to follow-up the information received about culprits and the culprits are arrested (IOL, 2018). The National Organisation for Albinism Hypopigmentation (NOAH), (2021) also indicated that neighbours and families, as well as friends of people with albinism, normally report cases of abuse to the police stations and Social Work Development when their beloved experiences abuse by their fellow citizens.

#### **6.4.2.3 Intervention Strategies for Combating Abuse and Killings of people with albinism**

The study concluded it was critical to elucidate the current intervention techniques in place to address the abuse experienced by people with albinism. In that light, the study discovered both people with albinism and social workers had similar views that law enforcement was in place and used to ensure that culprits responsible for imposing abuse and murder on people with albinism are detained.

In supporting the above sentiments, one person with albinism said, *“It is consoling that anyone who abuses us is jailed even though such people come out of jail after few years”*.

Another participant stated, *“The law enforcement is working with the community to help fight against those who are excited in abusing and killing us”*.

A social worker indicated, *“We have law enforcement in place to where cases of abuse and killings of people with albinisms are reported. I have been a witness on that for several times”*.

According to the United Nations (2013), law is enforced for the criminalisation of abuse against people with albinism and if culprits are not known, their investigation and the prosecution is severely executed to ensure that they are imprisoned. Nkrumah (2019) highlighted that African countries should take steps to guarantee that all perpetrators of abuse against persons with albinism are apprehended and prosecuted in order to ensure that the general public is aware that abuse against individuals with albinism is prohibited by international law.

Concerning albinism society or foundation, the study indicated that people with albinism and social workers were aware of an albinism foundation or society in place. It was discovered that the albinism society was found to be in charge of receiving all complaints and ensuring that people who have albinism are living a peaceful life in KwaZulu-Natal.

In supporting the above sentiments, one participant said, *“We have organisations like Masiqoqane Albinism foundation that were established by certain individuals to help people with albinism. These organisations are for people with albinism to report any case of abuse or murder”*.

One of the social workers said, *“The albinism society must be funded by government in order to be managed properly and to ensure that it tackles all cases of abuse against people with albinism”*.

The literature also showed that albinism societies play a crucial role in ensuring that incidences of mistreatment of persons with albinism are reported and that appropriate legal action is taken by the authorities (Mswela, 2017).

Regarding another intervention strategy, the study showed that both people with albinism and social workers indicated that awareness campaigns were also in place to ensure that the public is educated about abuse against people with albinism.

One of the people with albinism said, *“Even though in countries like Zambia, Tanzania etc. they moved all people with albinism into one shelter, in RSA we only have awareness campaigns. This campaign is sometimes on Ukhozi FM”*.

Another participant remarked, *“Currently, I only know the awareness campaign as a strategy in South Africa. This campaign is responsible for educating the public about our condition and that we are human beings like any other person”*.

One social worker said, *“We sometimes do awareness campaigns in schools and in the communities where the abuse of people with albinism is very high”*.

Organisations such as the International Albinism Awareness Day by the United Nations General Assembly (2015) also emphasised that awareness campaign should be meant to express concerns at the attacks against people with albinism including their children. Mswala (2016) concluded that raising awareness campaigns are necessary to provide substantial education aimed at behaviour change in order to address society's lack of knowledge and to dispel widespread myths that being albino is a curse and that the body parts of individuals with albinism have the ability to bring wealth.

#### **6.4.2.4 Debate over the Effectiveness of Intervention Strategies**

Regarding the debate over effectiveness of intervention strategies, the study found the intervention strategies were not enough to convince people with albinism feel safe in the province of KwaZulu-Natal. The study further identified several reasons on how the

intervention strategies could be ineffective. It was discovered that the intervention strategies were insufficient.

One participant remarked, *“The intervention strategies are not enough because people with albinism are still being abused and victimised on a daily basis due to the ignorance of people”*.

Another person with albinism said *“Not really, a lot of work still needs to be done especially in rural areas where these things mostly occur. There is no coverage that educate people about prohibition of abuse of people with albinism.”*

A study by Franklin et al. (2018:2) also pointed out people with albinism in African cultures perceive their circumstances as unfriendly because of the ineffectiveness of institutional and national initiatives. Nyamu (2020) also noted with concern that poverty, insufficient access to medical treatment, a lack of favourable learning environments and services, a lack of community empowerment, a lack of participation in community events, discrimination, and stigma all have an impact on the well-being of persons with albinism in Africa.

The study also revealed that there is a lack of consistent awareness campaigns in the province of KwaZulu-Natal.

One participant stated that, *“No, not everyone gets an invite to some of these awareness campaigns and the law seems to be very weak because a culprit is jailed only few months and after that the person is out. What is that really?”*

Another participant revealed that, *“No Sir, the problem with this country of ours is that awareness campaigns are done only if there are cases of abuse. It should be done at least every month.”*

A third participant commented and said, *“We have not enough awareness campaigns because these criminals are in rural communities and unfortunately, there is nothing happening in rural areas”*.

The literature study revealed that national governments worldwide are not pushing enough in making the public aware of the rights of people with albinism. In fact, all citizens need to be aware of the rights and freedom of people with albinism (Ero, Muscati, Boulanger & India, 2021).

The study findings exposed that the law enforcement in South Africa is very weak and that is one of the reasons perpetrators of abuse against people with albinism will continue with their dirty work.

One of the participants said, *“Not really, the law is very weak. You can’t kill a person and after six months in jail you are out. What’s that?”*.

Ero, Muscati, Boulanger and India (2021), and Franklin et al. (2018) also highlighted in their studies that national governments' law enforcement is ineffective because of the rapid release of criminals. The authors noted that criminals are not held in prison until they have served their whole sentence but are released before they have completely absolved themselves of their wrongdoings.

The study findings also pointed out that there is lack of policy that covers or protects people with albinism. The study showed that for all other people there is a policy in place, however, for people with albinism there is none.

One participant said, *“There is no policy that covers us as people with albinism”*. Another participant said, *“Not really, we do not have a policy that protect us. Women and children have their policies on abuse. Why can’t they do same to us”?*

Franklin et al. (2018) claimed that Africa lacks a robust policy to safeguard persons with albinism from the abuse that is imposed upon them in their daily lives. Mswela (2017) went on to complain that the public takes advantage of persons with albinism by abusing and murdering them because the rules in existence do not adequately

protect people with albinism and do not set out how perpetrators of abuse will be punished as justification.

The study also found that there is poor leadership in the country of South Africa as the issue of abuse against people with albinism is not adequately addressed by the government.

One person with albinism noted, *“We lack leadership in our country. Others are protected while we are left to struggle on our own.”*

Another person with albinism said, *“A real president cannot keep quiet when his people are abused and murdered. This thing is political. We don’t have leadership in our country, and this is like we are strangers in our own land.”*

Burke’s et al. (2014) also voiced that some governments may be trying to assist people with albinism, however, there are still issues such as not doing enough to protect the people with albinism, while others have poor support from leadership as people who are victims do not have a voice. Additionally, the study findings showed that the public is poorly advised regarding abuse against people with albinism.

One participant stated, *“The whole thing is confusing, it looks like when they address the issue of abuse against us, they are talking to us. What’s that? They should talk to the citizens because these people are heartless. Traditional healers who use body parts of animals and people should be stopped from operating that way. They are the ones doing this. They must be screened period”.*

The literature also showed that the public is not fully educated on the fact that people with albinism are also human beings who are disabled (Pooe-Moneymore, 2012).

### 6.4.3 Solution to Improve Intervention Strategies

Since the coping strategies that are in place have weaknesses, it was important for participants to discuss and indicate contextual solutions that needed to be adapted in order to enhance and improve intervention strategies in order to reduce and eliminate abuse and killings of people with Albinism. The study revealed a number of intervention strategies that can be adapted.

**Firstly**, the study showed that there is an urgent need for government to intervene in the abuse and killings of people with albinism.

One participant opined, *“Our government must intervene and assists because they look more relaxed, yet we are being killed and abused. Government cannot keep quiet at a time like this. She must intervene or else they will finish us in no time.”*

Another participant raised this concern and said, *“Our government is too quiet, yet she needs to intervene. I never heard the president of our country addressing this issue. What is the problem?”*

The United Nations General Assembly Security Council (2013) also pointed out that all countries should take steps and invest resources in initiating legal action against perpetrators of attacks against people with albinism, public condemnation of such attacks, temporary shelter for people with albinism who are threatened with attack, and public awareness raising campaigns.

**Secondly**, another solution from the study is educating people about albinism. The study revealed that there is an urgent need to educate the public about albinism that it is a disease like any other illness and that people with albinism should not be a prey to their fellow citizens.

One person with albinism said, *“People need to be educated more about people living with albinism, more and more communities need to be educated especially the older generation because it is them who perpetuate false beliefs to the younger generation”*.

In its document, the United Nations (2020) stated that the manner in which discrimination faced by persons with albinism is a result of a lack of education of the public. The organisation went on to state that educating the public is a necessity if countries really want to eradicate the abuse and killing of people with albinism.

**Thirdly**, the study also revealed that there is a need for the equal treatment of people with albinism. In other words, people with albinism felt they are not equally treated like any other citizens, thus equal treatment is urgently demanded.

One of the participants said, *“It is hard to say. The only thing needed is for everyone to restrain from inhuman thoughts and learn to treat us the way they want to be treated.”*

The United Nations (2020) called for the global community to respect people with albinism because they are also human beings. The information and literature discussed revealed the need for all global citizens to fight discrimination and murder of people with albinism and work towards a world free of discrimination, fear, violence and stigma.

Concerning the **fourth** solution, the study discovered that there is an urgent need for awareness campaigns that will cover the abuse and murder of people with albinism. The study opined that the awareness campaigns should be directed towards helping people with albinism where the public is educated that albinism is a condition or sickness.

One person with albinism commented, *“Campaigns on awareness of abuse and killings of people with albinisms must be done on radios and television on monthly basis. Educating traditional healers that we have body parts like them”.*

Another participant said, *“It would be of great help if awareness campaigns were done all over the country but must be very intensive in rural areas, as people there are unaware of the condition”*.

The literature on this subject also indicated that there is an urgent need for awareness programmes aimed at educating society about the dangers of discrimination, abuse, and murder of people with albinism (United Nations General Assembly, 2015).

**Fifthly**, the study indicated that there is an urgent need for a policy that protects all people with albinism.

One person with albinism said, *“We need a written policy that protects us just like countries Tanzania where the citizens have a policy in place. This abuse and murdering of people with albinism would come to an end if such is implemented”*.

According to the 1948 Universal Declaration of Human Rights, there shall be no person kept in slavery or servitude; slavery and the slave trade shall be abolished in all their manifestations. This indicates that no one should be regarded as a slave, as all human beings are equal regardless of their origins or skin colour. It is self-evident that people have the right to freedom of movement and residence within the borders of each state if they are not treated as slaves. They have the right to leave and return to any country, including their own (Universal Declaration of Human Rights, 1948).

With regard to the **sixth** solution, the study showed that the perpetrators of violence and killings of people with albinism is very sensitive, and these culprits must be sentenced for life in prison.

One person with albinism said, *“People who are found guilty of abuse and killings of people with albinism should be jailed for life (udilika jele). This can end myth that our body parts are a solution for their wealth”*.

According to the European Parliament (2018), all African government authorities must take proactive measures against any criminal organisation or individual engaged in witchcraft or human trafficking, provide adequate training and resources to police, thoroughly investigate albinism-related crimes, end impunity, and seek urgent international assistance to conduct impartial and effective investigations into all reported attacks against people with albinisms.

As a **seventh** solution, the study indicated that all traditional healers who use body parts of human beings and animals should be banned from being healers for they are abusing and killing people with albinism.

One person with albinism noted that, *“Everyone should have access to information about albinism. The government should deal with traditional healers who use body parts to treat problems of people. We are not supposed to be killed in order to cure someone’s problem. In reality, these traditional healers deserve to be in custody”*.

The literature on this topic also pointed out that a violator of other citizens' rights, particularly those of the disabled, is subject to the death sentence, according to the Universal Declaration of Human Rights (1948). Traditional healers who use the body parts of people with albinism in rituals, according to Baker (2018), should be detained and barred from practicing as traditional doctors in any capacity.

#### **6.4.3.1 Professional Bodies Providing Counselling**

Regarding professional bodies providing counselling to people with albinism especially victims, the study indicated there are several bodies helping people with albinism. Both people with albinism and social workers revealed that social workers were providing emotional counselling to some people with albinism who had been abused or witnessed abuse.

One of the people with albinism said, *“I received counselling from the hospital where a social worker was invited to address my emotions which were uncontrollable”*.

A social worker said: *“I provide psychological counselling and also empower them with skills to bounce back themselves without being helped by us because that is my office as a social worker”*.

Secondly, the study showed that both people with albinism and social workers revealed that a professional body of psychologists help counselling people with albinism. The study showed that professional psychologists play a very crucial role in counselling victims of abuse who are in a very serious trauma.

One person with albinism said, *“Psychologist play a crucial role in counselling us as we are unable to cope emotionally and psychologically especially after you have been abused or witnessed the abuse of our brothers and sisters. We become traumatised emotionally and psychologically”*.

The International Federation of Social Workers (2014) also revealed that social workers, together with psychologists, are considered as professionals whose responsibility is to provide counselling to ensure that they deal with a root cause of the problem. The study also showed that people with albinism who are victims of abuse receive counselling from the albinism society.

One participant was pleased to say, *“We have albinism society, and it is very helpful in case we experience trauma. For example, I received psychological counselling from the Albinism society for many times”*.

Mswela (2017) also supporting the study findings by stating that an albinism society is essential in ensuring that incidences of mistreatment of persons with albinism are reported and that appropriate legal action is taken by the authorities.

#### **6.4.4 Helpfulness of counselling received**

As the study indicated that people with albinism are receiving counselling from professional bodies, the study had to dig deep regarding the helpfulness of counselling

received from the professional bodies. Noticeably, the study showed that after people with albinism had received counselling from the professional bodies, a large number of them normally cope well.

A participant said, *“The counselling I received was really helpful, even though you cannot be at peace knowing that anything can happen”*.

One participants revealed, *“I coped from psychological, emotional and emotional stress, however, the situation has not changed completely”*.

The literature also showed that the profession of social work addresses cases of victims of abuse in a society to ensure that counselling is provided to eliminate stress and mental disorders (NASW, 2008). As much as many victims of albinism indicated that they are coping, the study also discovered that there are some people with albinism who are victims of abuse who are unable to cope with psychologically and emotionally.

One participant said, *“Even though I have received counselling emotionally and psychologically, it is very hard me to cope. I can be murdered anytime. This problem is still existing”*.

Mswela (2017) also stated that people with albinism are unable to deal with the abuse that they suffer on their own since it is beyond their ability.

## **6.5 RECOMMENDATIONS FOR RELEVANT STRATEGIES TO COMBAT THE ABUSE AND KILLINGS OF PEOPLE WITH ALBINISM**

Having discussed the effectiveness of intervention strategies and other means of alleviating abuse against people with albinism, the study had to come up with recommendations in a form of relevant strategies to combat the abuse and killings of people with people with albinism. From the findings it is recommended that:

### **6.5.1 Recommendations for Social Work Practice**

Social work is a profession and a field of study that seeks to improve society as a whole by fostering cohesiveness as well as individual agency and freedom. The principles of social work are human rights, social fairness, civic duty, and respect for differences (Healy, 2005). The Ecological Systems Theory by Urie Bronfenbrenner (1977) and Resilience Model by Masten, Best and Garmezy (1990) are commended for social work practice models based on their effectiveness in addressing key issues of the abuse and killing of people with albinism. The two models are able to show a clear picture on how a community affected by abuse can be rescued. Empowerment of social workers dealing with the abuse and murdering of people with albinism needs to be strengthened to ensure that they are familiar with the cases of this nature.

### **6.5.2 Recommendations for Social Work Curriculum**

The curriculum is a systematic sequence of anticipated teaching outcomes and accompanying learning experiences, which is typically organised as a connected grouping of courses. The curriculum is used to create, organise, and plan an education or training action, including the determination of learning objectives, content, techniques (including assessment), and materials, as well as arrangements for teacher and trainer training (CEDEFOP, 2011). The study made several recommendations of the social work curriculum:

- There is an urgent need for the generic social work curriculum to be strengthened with social work interventions in cases of the abuse and murdering of people with albinism, as all social workers are expected to deal with cases of people with albinism as these are new cases spreading worldwide.
- There is an urgent need for the training of all social work practitioners who are already in the field because it is the responsibility of all professional social workers to be responsible for intervening in cases of abuse in rural communities.

- It is also important to ensure that students who practise to be social workers are trained on this and also allowed to attend workshops that will empower them and prospective researchers.

### **6.5.3 Recommendations for Social Work Policy**

Social work is a practice-based profession that is embedded in legislative frameworks aimed at promoting social change and development, social cohesion, and the empowerment and liberation of people to improve their lives and wellbeing (NASW, 2008; International Federation of Social Workers (IFSW), 2014). The following recommendations could be made in terms of social work curriculum, policy and legislation:

- There is an urgent need to provide training to service on the available policy or constitution dealing with people with disabilities such as people with albinism.
- There is an urgent need to create awareness to the whole nation of South Africa which should be conducted through media such as local radio stations, newspapers, television and through seminars and workshops about the abuse and murder of people with albinism.
- Informing traditional healers who use body parts in their practice that there is a constitution which prohibits traditional healers from using body parts of human beings and animals.

### **6.5.4 Recommendations for Self-Defence Classes**

The people with albinism who are victims of abuse and killings recommended that they needed to be trained to be able to defend themselves in case they should face an attempt of abuse and/or murder from their fellow citizens. They emphasised an urgent need from government to provide them with training in self-defence.

### **6.5.5 Recommendations to Strengthening of Awareness Campaign**

The people with albinism and social workers also recommended that the government, the private sector, non-governmental organisations, the church and other partners should support and strengthen the awareness campaigns on the abuse and killing of people with albinism. They strongly believed that this would enable the society to have correct information on the condition that would reduce incidences of stigma and discrimination. Mwsela (2016) also recommend that awareness and educational campaigns are required to bring an end to superstitious beliefs, discrimination and stigma that people with albinism's body parts can solve many problems in the life of an individual.

### **6.5.6 Recommendations for Constitution for People with Albinism**

The people with albinism and social workers recommended that the government should review the current Disability Act to include people with albinism as a disability so that they are recognised and respected just like everyone else. This means that the government needs to urgently include a legislation that protects people with albinism against public abuse and murder. The Universal Declaration of Human Rights (1948) also confirms that there shall be no person kept in slavery or servitude; slavery and the slave trade shall be abolished in all their manifestations.

### **6.5.7 Recommendations to Educate the Public about Albinism**

The government of South Africa should fully support funding programmes that are meant to equip the public concerning the abuse and murder of people with albinism. The people with albinism also stated that educating the public about albinism would enable society to have correct information on the condition and that would reduce incidences of stigma and discrimination as well as murder. According to the United Nations Human Rights Council Advisory Committee (2014), a lack of education amongst the public on the abuse against people with albinism is missing in many counties, especially in Africa. The United Nations (2020) continues to point out that the

manner in which discrimination faced by persons with albinism is as a result of lack of education of the public.

#### **6.5.8 Recommendations for Equal Rights for People with Albinism**

The people with albinism requested an urgent intervention of the government to inform the public that people with albinism have equal rights, just like any other South African in the country. The participants felt that the public is not recognising that people with albinism are also human beings and should be treated as such, hence they are now demanding that they need to be treated equally like all other human beings.

#### **6.5.9 Recommendations for Banning Traditional Healers Using Human Body Parts**

The people with albinism recommended that there is an urgent need to ban all traditional healers who use human body parts to treat their customers. The participants further stated that traditional healers who use human body parts and animal parts should never be regarded as community doctors, but rather must be sent to jail. They felt that the traditional healers perpetrated the killing of people with albinism because they want to make money from the innocent public.

*One participant said, "We need to come up with a strategy that will teach people about albinism, especially about cultural beliefs that are false. Traditional healers using body parts of human beings must be banned. They are very evil."*

#### **6.5.10 Recommendations for Albinism Society**

The last recommendation came from social workers that there is an urgent need for albinism society that should be responsible for all complaints and handling of cases of people with albinism. This recommendation was in-line with Mswela (2017), who also recommended that the albinism society is critical in ensuring that incidences of mistreatment of persons with albinism are reported and that appropriate legal action is taken by the authorities.

## 6.6 CONCLUDING REMARKS

The study sought to recommend intervention strategies to address the abuse and brutal killings of people with albinism in the province of KwaZulu-Natal, South Africa. The study established that persons with albinism are fully aware of the abuse and killing of people with albinism, in general. The study showed that the key informants (people with albinism) had once been abused and/or witnessed abuse against their fellow brothers and sisters. In that light, the study revealed that social workers and people with albinism agreed that people with albinism are discriminated against because of their skin colour and are labelled with different names. Additionally, the study proved that social workers and people with albinism were of the opinion that the victims of abuse usually suffered from emotional, physical and sexual abuse, as well as killings.

The study discovered that the factors contributing to abuse and brutal killings of people with albinism are not limited to lack of awareness, cultural beliefs and practices, as well as inadequate knowledge on people with albinism. Of importance to note is that the study showed that the body parts of people with albinism are believed useful for concoctions (muti). This means that their body parts are used to brew a strong mixture (muthi) that has “extraordinary qualities to heal and to bring fortune in one’s life”. Additionally, the study discovered that it is believed that the body parts of people with albinism are also very effective in growing business opportunities and bringing about enrichment and luck. The study concluded that it is believed that people with albinism’s body parts are essential in making people rich financially. Apart from using their body parts, the study established that it is believed that having sexual intercourse with a person with albinism eliminates or cure HIV/AIDS for those infected. Hence, the study concluded that once people with albinism had experience or witnessed abuse and killing of their beloved ones, they become fearful and unable to socialise nor trust the public.

Moreover, the study showed that once people with albinism have experienced or witnessed abuse, their self-esteem diminishes and those who are women prefer to live as single rather than getting married because they do not trust anyone anymore.

Having chosen this kind of life, they suffer from psycho-social, emotional and psychological consequences as a result of the abuse perpetrated by their fellow citizens. Despite the fact that people with albinism live in fear, it was discovered that they have a very strong support from family members and teachers who provide them with first aid help. Moreover, SASSA was also noted to be helpful in providing people with albinism with a financial grant to eliminate poverty. The study concluded that the reason serious cases of abuse of people with albinism are known is because such cases are reported to social workers, police-stations, families and neighbours as well as schools.

To conclude, the study established that Government needs to be fully involved in raising awareness of the abuse of people with albinism. Additionally, the study concluded that educating the public on the condition of albinism is crucial as it would empower society with the knowledge that having albinism is a disability and a sickness. Banning traditional healers who use body parts of human beings and animals is crucial because it is believed that they perpetrate the abuse and killings of people with albinism.

The study also wishes to conclude that equal treatment of people with albinism is equally important just like any other person in the country. In other words, people with albinism felt they are not equally treated like any other citizen, thus equal treatment is urgently demanded.

## **6.7 Limitations of the study**

- The researcher collected data during covid-19 and participants were not open enough to discuss their social life as they felt threatened by the issue of covid-19.
- The researcher found it difficult to collect data during covid-19, especially during lockdown as social workers were not available in their offices to be consulted. The researcher had to rely on his friends who had also friends who were social workers. I was referred to them and I had to do interviews telephonically as they

also feared that they might contaminate the deadly disease.

- The researcher had to carry masks and sanitisers to those who agreed to honour the interviews personally. The face masks and sanitisers were meant to prevent the spreading of covid from one person to another.

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## APPENDICES

### APPENDIX 1: ETHICAL CLEARANCE

**UNIVERSITY OF ZULULAND  
RESEARCH ETHICS COMMITTEE**  
(Reg No: UZREC 171110-030)



#### RESEARCH & INNOVATION

Website: <http://www.unizulu.ac.za>  
Private Bag X1001  
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#### ETHICAL CLEARANCE CERTIFICATE

Certificate Number	UZREC 171110-030 PGD 2021/7				
Project Title	Development of intervention strategies to address the abuse and brutal killings of People Living with Albinism in KwaZulu-Natal				
Principal Researcher/ Investigator	M.M Shabalala				
Supervisor and Co- supervisor	Prof A.L Shokane				
Department	Social Work				
Faculty	Arts				
Type of Risk	High Risk – Study involves vulnerable people				
Nature of Project	Honours/4 <sup>th</sup> Year	Master's	Doctoral	x	Departmental

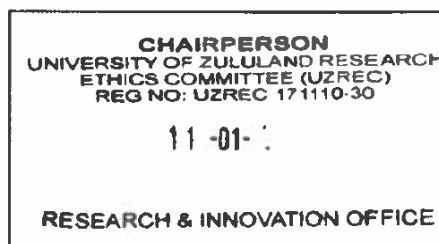
The University of Zululand's Research Ethics Committee (UZREC) hereby gives ethical approval in respect of the undertakings contained in the above-mentioned project. The Researcher may therefore commence with data collection as from the date of this Certificate, using the certificate number indicated above.

- Special conditions:
- (1) This certificate is valid for 1 year from the date of issue.
  - (2) Principal researcher must provide an annual report to the UZREC in the prescribed format (due date-11 January 2022)
  - (3) Principal researcher must submit a report at the end of project in respect of ethical compliance.
  - (4) The UZREC must be informed immediately of any material change in the conditions or undertakings mentioned in the documents that were presented to the meeting.

The UZREC wishes the researcher well in conducting research.

  
Professor Mashupye R. Kgaphola  
University Research Ethics Committee  
Deputy Vice-Chancellor: Research & Innovation

11 January 2021



## APPENDIX 2: PERMISSION FROM DEPARTMENT OF SOCIAL DEVELOPMENT



**KWAZULU-NATAL PROVINCE**

SOCIAL DEVELOPMENT  
REPUBLIC OF SOUTH AFRICA

DIRECTORATE: HUMAN RESOURCE UTILISATION & DEVELOPMENT

FAX	: 033 264 2075	174 Mayors Walk,
Telephone/ Ucingo /Telefoon	: 033 264 2078	Private Bag X9144
Enquiries / Imibuzo / Navrae	: Mr VW Gumede	<b>PIETERMARITZBURG</b>
E-mail	: Velaphi.Gumede@kzndsd.gov.za	3200
Reference no.	:	

**Mr M.M. Shabalala**  
**Social Work Department**  
**University of Zululand**  
**Kwa Dlangezwa**  
**3880**

Dear Sir

**PERMISSION TO CONDUCT RESEARCH UNDER ETHEKWINI METROPOLITAN AND UMGUNGUNDLOVU DISTRICT ON THE TOPIC ENTITLED "DEVELOPMENT OF INTERVENTION STRATEGIES TO ADDRESS THE ABUSE AND BRUTAL KILLING OF PEOPLE WITH ALBINISM IN KWAZULU-NATAL"**

This letter has reference

Kindly be informed that permission has been granted by the Head of Department for you to consult with Social Workers from the Department of Social Development in order to fulfill the requirements of your study.

The permission authorizes you to: -

- (a) Approach and distribute your survey questionnaires to Social Workers willing to participate to solicit information intended for your research and maintain high level of confidentiality.
- (b) Share your findings with the Department of Social Development.

**Wishing you success during your research project.**

  
HEAD OF DEPARTMENT

Date: 02/07/2021

## APPENDIX 3: PERMISSION THE NATIONAL ALBINISM SOCIETY GRANT



Mr M.M. Shabalala  
University of Zululand  
Department of Social Work  
Private Bag X 1001  
3886

**SUBJECT: PERMISSION TO COLLECT DATA FROM PEOPLE WITH ALBINISM**

The National Albinism Society grant permission to Mr Mbongeni Mfanasibili Shabalala to collect data from people with albinism as long as it does not harm people.

You are requested to ensure that all COVID-19 restriction is observed since it is still under lockdown level three.

Yours faithfully

03 July 2021  
Phumlani Mhlungu (071 920 3182)

*Chairperson of National Albinism Society*

## APPENDIX 4: PARTICIPATION CONSENT DECLARATION

### INFORMED CONSENT DECLARATION

(Participation)

Project Title: Development of Intervention Strategies to address the abuse and brutal killings of PWA in KwaZulu-Natal

Mbongeni M. Shabalala from the Department of Social Work; University of Zululand has requested my permission to participate in the above-mentioned research project. The nature and the purpose of the research project, and of this informed consent declaration has been explained to me in a language that I understand.

I am aware that:

1. The purpose of the research project is only for academic purposes
2. The University of Zululand has given ethical clearance to this research project and I have seen/may request to see the clearance certificate.
3. By participating in this research project I will be contributing towards helping raise awareness in the community on issues involving abuse and killings of people with albinism in KZN.
4. I will participate in the project by agreeing to be interviewed
5. My participation is entirely voluntary and should I at any stage wish to withdraw from participating further, I may do so without any negative consequences
6. I will not be compensated for participating in the research
7. There may be risks associated with my participation in the project. I am aware that:
  - a. The following risks are with my participation: Expressing my views on the matter may elicit feelings of discomfort
  - b. the following steps have been taken to prevent the risks: The researcher will allow a moment of debriefing after the interview; where I will talk about how I felt expressing my views on the subject matter
  - c. there is a 10 % chance of the risk materializing.
8. The researcher intends publishing the research results in the form of articles in journals however, confidentially and anonymity of records will be maintained and that

my name and identity will not be revealed to anyone who has not been involved in the conduct of the research.

9. I will receive feedback in the form of verbal feedback recorded on the tape recorder

Regarding the results obtained during the interview.

10. Any further questions that I might have concerning the research or my participation will be answered by the researcher: Mfanasibili Shabalala

11. By signing this informed consent declaration I am not waiving any legal claims, rights or remedies.

12. A copy of this informed consent declaration will be given to me, and the original will be kept on record.

#### PARTICIPANT'S REPLY SLIP

I, \_\_\_ have read the above information /

confirm that the above informed has been explained to me in a language that I understand and I am aware of this document's contents. I have asked all questions that I wished to ask and these have been answered to my satisfaction. I fully understand what is expected of me during the research.

I have not been pressurised in any way and I voluntarily agree to participate in the above-mentioned project.

.....  
Participant's signature      Date

Additional consent, where applicable:

I hereby grant permission to:	Please tick✓ to grant permission.
Audio-record and video-record my interview.	
Be provided with sanitizer, will sit approximately 2 metres away from the researcher and use a mask throughout the duration of the interview	

## APPENDIX 5: DEMOGRAPHIC DATA AND INTERVIEW GUIDE- PEOPLE WITH ALBINISM

### SECTION A: Demographic Data of Participants

Please tick (√) the relevant option

Age groups	(√)	Education level	(√)
18-30 years		Grade R-3	
31-40 years		Grade 4-6	
41-60 years		Grade 7-9	
61-70 years		Grade 10-12	
Older than 70 years		Tertiary education	
		Never been in school	

Gender	(√)	How long have you lived in KwaZulu-Natal?	(√)	As a person living with albinism, are you aware of the abuse against people living with albinism in the province of KwaZulu-Natal?	(√)
Male		Less than 12 months		Yes	
Female		2 years-3 years		No	
		4 years- 6 years			
		7 years-10 years			
		More than 10 years			

Employment Status?	(√)	Have you ever experienced abuse due to you being a person living with albinism in your life?	(√)
Student		Yes	
Employed		No	
Unemployed			

## **SECTION B: INTERVIEW GUIDE QUESTIONS FOR PWA**

1. What types of abuse are you aware of, that are levelled at PWA?
2. Which types of abuse have persons with albinism reported to you, have you observed or heard about?
3. In your view, what factors contribute to the abuse and brutal killing of people living with albinism?
4. Please share some of the places where the abuse and brutal killing of people living with albinism takes place?
5. How has the abuse and killing of people living with albinism affected you, your family and your life?
6. How did you or how do you cope (psychologically, financially, emotionally) with the abuse/trauma levelled at PWAs that you have experienced/heard about/witnessed or observed?
7. What types of counselling or assistance have you received after you experienced/heard about or observed the abuse or murder of PWA?
8. Who and where did you receive counselling or assistance from after experiencing, hearing about or observing the abuse and murder of PWA?
9. What was helpful about the counselling or assistance you received? Please explain
10. Were any aspects of counselling or assistance you received, negative?
11. What kind/s of counselling or assistance would you like to assist you cope?
12. What intervention strategies do you know of that are available to combat or prevent the abuse and killing of people living with albinism?
13. Do you feel that these interventions are enough/sufficient to prevent/combat the abuse and murder of PWA?
14. Are these interventions enough to prevent the abuse and killing of PWA?
15. What can be done/strategies can be implemented to reduce/eliminate the abuse, murder and trafficking of PWAs?
16. What intervention strategies would you propose to combat the abuse and killing of people living with albinism?
17. How can these intervention strategies to combat the abuse and killing of people living with albinism, be implemented?

## APPENDIX 6: DEMOGRAPHIC DATA AND INTERVIEW SCHEDULE SOCIAL WORKERS

### SECTION A: Demographic Data of Participants (Social Workers)

Please tick (✓) the relevant option

Age group	TICK✓	Education level	TICK✓
18-30 years		Grade 12	
31-40 years		BA Social Work	
41-60 years		BA Social Work Honours	
61-70 years		Postgraduate Degree	
Older than 70 years		Masters	
		PhD	

Gender	TICK✓	How long have you assisted/counselled/dealt with PWA in KwaZulu-Natal?	TICK✓
Male		2 years-3 years	
Female		4 years- 6 years	
		7 years-10 years	
		More than 10 years	

As a social worker are you aware of the abuse and killing of PWA in KwaZulu-Natal?	TICK✓	Have you ever witnessed abuse or killing of a person living albinism in your life time?	TICK✓
Yes		Yes	
No		No	

## REVIEW GUIDE QUESTIONS FOR SOCIAL WORKERS

1. What types of abuse have PWA reported to you or attended counselling for?
2. In your view, what factors contribute to the abuse and brutal killing of people living with albinism?
3. Can you share some of the places where PWA have told you the abuse and brutal?
4. How does the abuse and killing of PWA affect the PWAs that seek your assistance or counselling?
5. How did/do they cope (psychologically, financially, emotionally, socially) with the abuse/trauma they have experienced/heard about or seen?
6. What types of counselling or assistance have they sought/ received after experiencing/hearing about or observing the abuse or murder of PWA?
7. What interventional steps do you take as a social worker to address their challenges?
8. Who and where do PWAs receive counselling or assistance from after experiencing, hearing about or observing the abuse and murder of PWA?
9. In your opinion, what aspects about the counselling or assistance you render would you consider helpful?
10. In hindsight, were any aspects of the counselling or assistance you rendered, negative?
11. What intervention strategies do you know of that are /does the social work profession have available to combat or prevent the abuse and killing of PWA?
12. Do you feel that these interventions are enough/sufficient to prevent/combat the abuse and killing of PWA?
13. Are these interventions enough to prevent the abuse and killing of PWA?
14. In your opinion, what can be done/strategies can be implemented to reduce/eliminate the abuse and murder of PWAs?
15. What intervention strategies would you propose and recommend to combat the abuse and killing of PWA?
16. How can these intervention strategies of abuse and killing of PWA be implemented?

## APPENDIX 7: A SAMPLE RAW DATA: INTERVIEWS WITH PWA PARTICIPANTS

*Participant Thabeni*

### SECTION A: PARTICIPANTS DEMOGRAPHICS DATA

Kindly  place a tick next to the relevant option.

GENDER	<input checked="" type="checkbox"/>	AGE GROUPS	<input checked="" type="checkbox"/>	EDUCATION LEVEL	<input checked="" type="checkbox"/>
Male (M)		18-30 years	<input checked="" type="checkbox"/>	Grade R-3	
Female (F)	<input checked="" type="checkbox"/>	31-40 years		Grade 4-6	<input checked="" type="checkbox"/>
		41-60 years		Grade 7-9	
		61-70 years		Grade 10-12	
		Older than 70 years		Tertiary education	
				Never attended school	

HOW LONG HAVE YOU LIVED IN KWAZULU-NATAL?	<input checked="" type="checkbox"/>	AS A PERSON LIVING WITH ALBINISM, ARE YOU AWARE OF THE ABUSE AND KILLING AGAINST PEOPLE LIVING WITH ALBINISM IN KWAZULU-NATAL?	<input checked="" type="checkbox"/>	HAVE YOU EVER EXPERIENCED ABUSE DUE TO YOU BEING A PERSON LIVING WITH ALBINISM IN YOUR LIFE?	<input checked="" type="checkbox"/>
Less than 12 months		Yes	<input checked="" type="checkbox"/>	Yes	<input checked="" type="checkbox"/>
2 years - 3 years		No		No	
4 years - 6 years	<input checked="" type="checkbox"/>				
7 years - 10 years					
More than 10 years					

ARE YOU EMPLOYED OR UNEMPLOYED	<input checked="" type="checkbox"/>	WHAT IS YOUR OCCUPATION?
Employed		
Unemployed		
<i>Student</i>	<input checked="" type="checkbox"/>	

## SECTION B: INTERVIEW GUIDE SCHEDULE

1. Are you aware of abuse against people who are living with albinism?

Yes

2. Have you experienced abuse due to you being a person living with albinism?

Yes

3. What kinds of abuse have you experienced due to you being a person with albinism?

I have been labelled and discriminated against because of my skin color. I am constantly insulted and called derogatory names like this albino thing and monkey

4. In your view, what factors contribute to the abuse and brutal killing of people with albinism?

Lack of enough knowledge and information about albinism.

5. How has the abuse and killings of people with albinism affected you and your life?

I am affected psychologically

4. How have you coped (psychologically, emotionally, financially) with the trauma surrounding the abuse you experienced or the murders you observed, read or heard about?

I am supported by my teachers and I do not let myself.

5. Which intervention strategies do you know of that are available to combat or prevent the abuse and killing of people with albinism?

people who abuse us or put us in jail

6. Are these interventions enough to prevent the abuse and killing of people with albinism? Please explain.

not really, the law is very weak. You can't kill a person and after 6 months in jail you are out.  
What is done?

7. In your own opinion what can be done to improve the intervention strategies to reduce and eliminate the abuse of people with albinism?

It would be great help if awareness campaigns were done all over the country but must be very intensive in rural areas as people there are unaware of the condition

8. Who did you receive counselling from and what kind of counselling did you receive?

psychologist help phone

9. Please explain the different kinds/types of counselling you received after experiencing abuse or observing, reading or hearing about the murder and brutal killing of PWA?

stress counselling

10. Explain what you found helpful about the counselling you received?

Really difficult to cope

11. Elaborate on any aspect of the counselling that you received that you found unhelpful or insensitive?

12. What strategies would you propose to combat the abuse and killing of people living with albinism?

The public need a lot of education about albinism because they think we not human beings. They must know that albinism is a condition that can affect anyone at any time

Participant 2 Thekwini

**SECTION A: PARTICIPANTS DEMOGRAPHICS DATA**

Kindly  place a tick next to the relevant option.

<b>GENDER</b>	<input checked="" type="checkbox"/>	<b>AGE GROUPS</b>	<input checked="" type="checkbox"/>	<b>EDUCATION LEVEL</b>	<input checked="" type="checkbox"/>
Male (M)		18-30 years	<input checked="" type="checkbox"/>	Grade R-3	
Female (F)	<input checked="" type="checkbox"/>	31-40 years		Grade 4-6	<input checked="" type="checkbox"/>
		41-60 years		Grade 7-9	
		61-70 years		Grade 10-12	
		Older than 70 years		Tertiary education	
				Never attended school	

<b>HOW LONG HAVE YOU LIVED IN KWAZULU-NATAL?</b>	<input checked="" type="checkbox"/>	<b>AS A PERSON LIVING WITH ALBINISM, ARE YOU AWARE OF THE ABUSE AND KILLING AGAINST PEOPLE LIVING WITH ALBINISM IN KWAZULU-NATAL?</b>	<input checked="" type="checkbox"/>	<b>HAVE YOU EVER EXPERIENCED ABUSE DUE TO YOU BEING A PERSON LIVING WITH ALBINISM IN YOUR LIFE?</b>	<input checked="" type="checkbox"/>
Less than 12 months		Yes	<input checked="" type="checkbox"/>	Yes	<input checked="" type="checkbox"/>
2 years - 3 years		No		No	
4 years - 6 years					
7 years - 10 years	<input checked="" type="checkbox"/>				
More than 10 years					

<b>ARE YOU EMPLOYED OR UNEMPLOYED</b>	<input checked="" type="checkbox"/>	<b>WHAT IS YOUR OCCUPATION?</b>
Employed		
Unemployed		
Student	<input checked="" type="checkbox"/>	

## SECTION B: INTERVIEW GUIDE SCHEDULE

1. Are you aware of abuse against people who are living with albinism?

yes

2. Have you experienced abuse due to you being a person living with albinism?

yes

3. What kinds of abuse have you experienced due to you being a person with albinism?

I am scared of walking in public with pride scared of walking in the streets freely?

4. In your view, what factors contribute to the abuse and brutal killing of people with albinism?

people want to be new by the organs of albinos

5. How has the abuse and killings of people with albinism affected you and your life?

I am no longer a free but in prison.

4. How have you coped (psychologically, emotionally, financially) with the trauma surrounding the abuse you experienced or the murders you observed, read or heard about?

I always motivate myself even though thoughts keep running in my head.

5. Which intervention strategies do you know of that are available to combat or prevent the abuse and killing of people with albinism?

To do awareness campaign at schools

6. Are these interventions enough to prevent the abuse and killing of people with albinism? Please explain.

There is no one to enforce law to people who kill all people with albinism.

7. In your own opinion what can be done to improve the intervention strategies to reduce and eliminate the abuse of people with albinism?

We are not medicine for another person's problem, people must be educated.

8. Who did you receive counselling from and what kind of counselling did you receive?

Family made play a big role by providing counselling.

9. Please explain the different kinds/types of counselling you received after experiencing abuse or observing, reading or hearing about the murder and brutal killing of PWA?

Trauma counselling

10. Explain what you found helpful about the counselling you received?

Even though I have received counselling; emotionally and psychological it is very hard to life. I can't be ever murder anything.

11. Elaborate on any aspect of the counselling that you received that you found unhelpful or insensitive?

12. What strategies would you propose to combat the abuse and killing of people living with albinism?

The constitution must also be amended to include the protection of people with albinism.

## 9.8 APPENDIX 8: A SAMPLE OF RAW DATA: INTERVIEWS WITH SOCIAL WORKERS

*Social Worker 1*  
**APPENDIX : INTERVIEW GUIDE**

*Etho kuni*

### INTERVIEW GUIDE

Development of interventional strategies to address the abuse and brutal killings of people living with Albinism, KwaZulu-Natal

#### SECTION A: DEMOGRAPHIC DATA OF PARTICIPANTS

Age groups	Tick	Gender		Education level	Tick
18-29 years		Male		BA Social Work	✓
30-40 years		Female	✓	Masters in Social Work	
41-50 years	✓			PhD in Social Work	
51-65				Other post graduate qualifications	

How long have you been employed as a social worker?	Tick	What is your role as a social worker?	Tick
24 months and less			
2 years-5years			
6 years- 10years	✓		
11 years and above			

#### SECTION B: CONTEXTUAL QUESTIONS

Development of interventional strategies to address the abuse and brutal killings of people living with Albinism, KwaZulu-Natal

1. What kinds of abuse do people living with albinism experience?

*Their body parts are harvested.*

2. What do you think contributes to the abuse and killings of people living with albinism?

*I have heard many reports that some <sup>people</sup> ~~are~~ ~~the~~ ~~body~~ ~~parts~~ of people with albinism to get healed from HIV/AIDS*

4. How are cases of abuse against people living with albinism reported to you, as a social worker?

It is quite disturbing that people with albinism are subjected to such harsh treatment by their fellow countrymen and occasionally even such support from their neighbours and family members that they are going through tough times.

5. What interventional steps do you as a social worker to address the matter?

I provide counselling that is related to stress when people with albinism are unable to cope

6. What counselling do you provide to them to ensure that they are psychologically and emotionally healed?

I provide stress and traumatic counselling

7. What interventional strategies does the social work profession have in place to combat the abuse and killings of people living with albinism?

We sometimes do awareness campaigns in schools and in the community where the abuse of people with albinism is very high.

8. What kind of service(s) do you think needs to be provided to people living with albinism to ensure their safety?

Educating the public is very important to stop abusing the people with albinism.

9. What intervention strategies can be recommended to combat the abuse and killings of people living with albinism?

I think it is important for them to have a constitution then they can be safe.

Social work 2

APPENDIX : INTERVIEW GUIDE

Efeka

INTERVIEW GUIDE

Development of interventional strategies to address the abuse and brutal killings of people living with Albinism, KwaZulu-Natal

SECTION A: DEMOGRAPHIC DATA OF PARTICIPANTS

Age groups	Tick	Gender		Education level	Tick
18-29 years		Male		BA Social Work	✓
30-40 years	✓	Female	✓	Masters in Social Work	
41-50 years				PhD in Social Work	
51-65				Other post graduate qualifications	

How long have you been employed as a social worker?	Tick	What is your role as a social worker?	Tick
24 months and less			
2 years-5years			
6 years- 10years			
11 years and above	✓		

SECTION B: CONTEXTUAL QUESTIONS

Development of interventional strategies to address the abuse and brutal killings of people living with Albinism, KwaZulu-Natal

1. What kinds of abuse do people living with albinism experience?

They are being killed and called names

2. What do you think contributes to the abuse and killings of people living with albinism?

We always hear stories the public has strong cultural beliefs that using an eye of a person with albinism can make one prosper at work.

4. How are cases of abuse against people living with albinism reported to you, as a social worker?

we get information from police station about victims

5. What interventional steps do you as a social worker to address the matter?

It is our duty as social worker to provide counselling to people with albinism who are traumatised by the public

6. What counselling do you provide to them to ensure that they are psychologically and emotionally healed?

I always give them counselling on emotional and psychological.

7. What interventional strategies does the social work profession have in place to combat the abuse and killings of people living with albinism?

Provision of counselling is what we always do to ensure that our people are safe.

8. What kind of service(s) do you think needs to be provided to people living with albinism to ensure their safety?

I am aware that people with albinism have their safety be a major concern of police

9. What intervention strategies can be recommended to combat the abuse and killings of people living with albinism?

Albinism society must be really active to ensure that their voices is heard