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## When the community ceases to be a sanctuary : An Ethical and Theological reflection of the challenges facing families with children living with Albinism in South Africa

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## 27 When the community ceases to be a sanctuary

### An Ethical and Theological reflection of the challenges facing families with children living with Albinism in South Africa

*Zandile Ngubane & Beatrice Okyere-Manu*

#### Abstract

Ezra Chitando, a renowned scholar and theologian, has been concerned with the plight of the poor, vulnerable minority groups in African society. Several of his scholarly publications have been dedicated to exposing this plight and challenging the church and the community to work towards responding to it. Chitando's dream is to see that justice is granted to the vulnerable. One such vulnerable group in most African communities, that deserves justice and equal opportunities are people living with Albinism and their families, particularly mothers. They face many ethical, religious, and cultural challenges. Many within local communities perceive albinos as sub-humans and a special ingredient for self-enrichment concoctions. In light of this, the chapter presents analysis of 12 interviews with mothers and children living with albinism in order to understand their lived realities and experiences. Through the lens of the ethical theory of consequentialism, it emerged that many people living with albinism feel they have no right to life, they are not of the same worth and dignity as their peers, they are an endangered species as they are hunted by those seeking self-enrichment muthi. Therefore Chitando's call and advocacy for vulnerable groups must be extended to people living with Albinism.

**Keywords:** Albinism, Consequentialism, Church, Myths, People living with Albinism

#### Introduction

In almost all societies, there are some marginalized people. Among the poor and vulnerable groups in most African communities are people living with Albinism. According to Caradee Wright (2015:27), albinism is an inherited genetic disorder that affects individuals due to the absence of melanin. Elvis Imafidon also describes albinism as a condition affecting

living things, whether animals or plants, resulting from a lack of normal pigmentation. He continues that People with albinism appear to be visibly different from others of their kind (2017:9). In his book *African Philosophy and the Otherness of Albinism*, he explains that the lack of knowledge about this disorder has resulted in the community finding justification for the pigmentation. Consequently, this has led to misconceptions, myths, superstitions, and wrong beliefs about this disorder. There are several beliefs about the disorder, some of which contradict themselves. Some of these include the belief that people with albinism bring bad luck, while others believe that they can be used as a means of acquiring wealth. As a result, People with albinism are an outcast in the communities within most of the African communities. It is difficult for people to accept what is different from the usual. Hence, PWA is referred to as “it” or perceived as the “other”. Imafindon (2017; 2018). Several scholars have written about the different beliefs associated with albinism. For example, Bradbury-Jones (2018:8) conducted a study to discover people’s perceptions of albinism. This study interviewed an equal number of people who are living with albinism and without albinism. Some of the people in this study shared that they were taught to believe that when someone who is HIV & AIDS positive has sexual intercourse with a person living with albinism they will be cured of the virus (2018:8).

There are different forms of Albinism, and Abeshi et al. (2017:81) and Wright et al. (2015:27) affirm that the prevalent form of albinism in Sub-Saharan Africa is Melanosomal transmembrane protein or OCA2. This type of albinism is characterized by lightly pigmented hair, skin, eyelashes, and eyebrows. The lack of melanin affects one (1) in four thousand (4000) people in Sub-Saharan Africa, Salewi (2011:01); Ross (2015:01), suggesting that they are a minimal group of people in most African communities. However, there are about seven different types of albinism.<sup>1</sup>

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<sup>1</sup> A comprehensive description and explanation of the various types is found in (NOAH 2014; et al., Abeshi 2017 and Wright et al. 2015). Tyrosinases related Albinism is commonly called OCA1. It is a result of a genetic shortcoming in an enzyme called tyrosinase. This kind of condition is divided into two subtypes OCA1a and OCA1b, which leads to white hair that may darken to blond, yellow or somewhat orange or light brown hair. This includes slightly more pigment in the skin. OCA2 albinism, is Protein genetic albinism. It is as a result of a genetic defect in the protein that helps the tyrosinase enzyme to function. This type is of Albinism is commonly found in Sud-Saharan Africa. OCA3 is a mild subtype and is characterised by reddish hair and It has an estimated prevalence of 18,500 in Africa. It is rarely seen in other populations.

Martin Nelwan (2018:01) posits that each type varies by the type of genetics that need to meet or be absent in the parents to produce a certain kind of albinism. As has been noted, of all the seven, the most common type in Sub-Saharan Africa is OCA2 (Abeshi et al. 2017:81).

An individual's chromosomes must carry the trait for this condition to be present. This implies that individuals with albinism typically inherit traits from both parents (mother and father), who often have normal pigmentation. For there to be an Albino child, both are regarded as carriers of the albinism trait because they each possess a recessive gene for the condition. However, they may not exhibit the condition themselves. When both parents carry the albinism gene, each pregnancy has a one in four chance of having a child with albinism. This mode of inheritance is called "autosomal recessive" inheritance (Noah 2014:4).

As a minority group, children living with Albinism face several challenges because they differ from other children. Being a person living with Albinism, Elvis Imafidon affirms this by saying that "broadly construed, albinism is socially and culturally representation (represented?) as an unwelcome abnormality or difference, much the same way as other forms of disability are negatively designated in African tradition" (2018:19). He further explains that "Africans are unable to cope with, and, unwilling to accept anything different or unusual from status quo" (Imafidon 2018:165). His experiences underscore that traditional African people have a negative attitude toward unfamiliar things or something different from the norm. People living with Albinism are perceived as ghosts, so the children and their families are unsafe in their communities. They are discriminated against and constantly live in a state of fear. Salewi (2011) and Mswela (2017) have argued that individuals with albinism and their families are

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The street name for this type of albinism is ginger. Individuals with OCA4 are usually recognized in the first year of life and generally have some hair pigment with the colour ranging from silvery white to pale gold. The colour of the hair may darken with age but does not vary significantly from childhood. This condition is as a result of a genetic defect in the SLC45A2 protein that helps the tyrosinase enzyme to function. People with OCA4 make a minimal amount of melanin pigment similar to people with OCA2.

The identification of Type OCA5-OCA7 in humans occurred in 2012 and 2013, revealing mutations in three more underlying genes. With the growing availability of gene testing and the increasing identification of individuals affected by these forms of albinism, a comprehensive spectrum of physical traits will be acknowledged, possibly intersecting with other established types of OCA.

subjected to violence and attacks based on misunderstandings about their condition. They cannot lead ordinary lives and are often afraid to integrate into their communities.

With this background, the current chapter interrogates the experiences of ten families headed by women in Gauteng and KwaZulu-Natal in South Africa. Informed by the ethical theory of consequentialism and the experiences of ten families, the chapter affirms the humanity of the people living with Albinism and argues that they deserve the justice that Ezra Chitando seeks for the poor and minority in our communities. The justice that people living with Albinism require condemns the fear, stigmatization, and discrimination against families with children living with Albinism. It challenges the religious and cultural leaders of the communities to take the issues surrounding people living with Albinism seriously. The chapter is divided into four sections; first is the introduction, then the methodology employed in the study. This is followed by a discussion of the ethical and theological reflections on the challenges faced by people living with Albinism, followed by a conclusion.

## **Methodology**

The chapter uses a narrative method to present the stories of ten families from Johannesburg and Pietermaritzburg in South Africa over 12 months. These sites were selected based on the recommendation from the Albinism Society in South Africa. The study employed qualitative data collection methods using in-depth interviews. Four families were interviewed in Pietermaritzburg and six in Johannesburg. An interesting observation was that women headed all the families interviewed. The women in the study are either divorced or neglected by their husbands or the father of their children. Of the ten women who participated, only three have formal education up to grade 10 and work as domestic workers. Seven of the women are unemployed. The authors spent about four months engaging with these women this allowed ample time to establish rapport and foster trust-based working relationships. A research guide comprising open-ended questions aimed at delving into the narratives and experiences of the family heads was used. By adopting a narrative approach, we align with the perspective of African feminist theologians, who emphasize the importance of providing African women a platform to share their stories. Oduyoye and Kanyoro (1992:1) aptly assert, "African

women theologians have come to realize that as long as men and foreign researchers remain the authorities on culture, rituals, and religion, African women will continue to be spoken of as if they were dead." Therefore, the narrative approach enabled the study participants to express their experiences openly. To protect their identities, pseudonyms were used. Due to the nature of the study, ethical clearance was obtained from the University of the KwaZulu-Natal ethical committee, and the Albinism Society of South Africa (ASSA) supplied a social worker and a counselor.<sup>2</sup> Participants were randomly selected because consent was voluntary since this interview was sensitive. Some participants volunteered to be part of the study through a radio interview by one of the writers of this chapter. Others were approached by ASSA and social media. The sensitivity of the research informed this selection choice and meant that everyone participating did not feel obligated to participate. The data was analysed using content analysis which according to Marriette Bengtsson, is a process where "data are presented in words and in themes, which makes it possible to draw some interpretation of the result (2016:10). Therefore, the next section presents the experiences of the study participants in themes.

### **Mothers face discrimination from the local community**

One important challenge that came out of our interview was the issue of societal exclusion. Alvis Imafidon explains why people with albinism are not accepted or seen as part of the community. He illustrates how the misconception about this disorder has resulted in stigmas and myths associated with albinism. He also emphasizes the community's language towards people with albinism and avows that this results from the community's lack of understanding of this condition. He asserts that "knowledge about albinism in African traditional and modern societies is damaged with systematic ignorance and falsehood that continue to serve as a veil that hinders the actual facts about albinism" (Imafidon 2018:71). He further explains that people living with albinism are seen as a threat to harmony. They are also perceived as harmful beings (Imafidon 2018:81). This assertion emerged strongly in the interview. For instance

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<sup>2</sup> This was a very difficult interview because of the trauma attached to it and also especially because one of the interviewees had to drop out because their child was killed.

Nombuso, a 32-year-old mother, affirmed the discrimination and marginalization from the community by saying that.

I don't want to be seen with my son in the community. It is difficult for me to allow my child to play with his peers in the community. It was hard for me to accept who he was. I am still learning too. At first, I was scared even to breastfeed my baby. I told my mother I had run out of milk and the best substitute would be best. I could not even look at him in the eye. I did not want to have any connection with the baby; my thoughts were that what if I bonded with him, connected to him, and lost him? I was afraid that he would disappear. We grew up believing that PWAs disappear into thin air or become animals. So, I did not want any attachments to him because he could disappear anytime. However, my mother was different and loved my child so much that she referred to him as a blessing, yet the entire family and I were convinced he was a curse. My mother would take him to the clinic, and I would remain home in anticipation. I remember one day, they spent the whole day at the clinic; the only thoughts in my mind were that they had been kidnapped on the way.

## **Families of Albinos live in fear**

All the families interviewed mentioned that the key challenge they face is fear. This is centred on what might happen to them and their children. The problem of fear is confirmed by the 2013 reports by "The Same Sun." It recorded that over the years, there have been an increasing amount of reported violent cases of albinism, and this has resulted in some families of people living with albinism leaving their homesteads in search of safe places because they are afraid of being attacked. They mentioned the fear of abduction and rape as their primary fear. For example, Lindiwe, a 50-year-old woman, said:

If I can tell you half of what I have been through because of my child, you would cry; sometimes, my child would not go to school for months because now and again, PWA has become a target, and many attacks are reported. For the first two years, my child was hidden, people knew there was a child in their area, but they did not see him until he started walking. When children started walking, no one can control them; I left my community because I feared people's thoughts. After all, the blame is pinned on the mothers. Most importantly, I fear what people could do to my child.

Busisiwe 48, Queen 40, and Dora 50 reiterated similar concerns. They fear for their daughters' lives. They stated that they fear the possibility of their daughters being raped. They reminded us of the myth that if one has sexual intercourse with PWA, one will be healed of HIV/AIDS. This has made them vulnerable and targets of rape. According to the UTSS organization, over the years, there have been an increased number of people living with Albinism who have reported rape cases (UTSS:2017). Zama maintained that "a mother with a child living with albinism needs to be extra vigilant about the child's whereabouts and places they visit to prevent them from falling victim to rape." Bila et al. (2015:02), in a similar vein, add that people living with albinism get raped often because people think that sleeping with a person with albinism cures one's HIV & AIDS infection. In addition to the above, Barker et al. (2010:172) and Machoko (2013:319) also confirm that people with albinism are attacked and raped because they are used to cure others of HIV & AIDS, diabetes, and cancer. This is as a result of the belief that PWA are supernatural or have supernatural powers.

Another form of concern shared by the interviewees is the fear of murder. They all mentioned that they live in constant fear because they do not know when they will hear that their children have been murdered. Recently, ritual murder has been widespread in most traditional communities. The murder has been in the form of human sacrifice practiced by some African tribes (Munthali 2005:29). There are strong indications of human body parts being used as ingredients in traditional medicine because they believe it will make strong *muti*. It involves the removal of the required body parts from the victim while the person is still alive (Labuschagne 2014:191-206). Makhosazane, a 40-year mother, said that:

My biggest fear is receiving a phone call one day reporting the passing away of my child, especially in a brutal way. I am from the North of Kwazulu-Natal, and we all know that people in that area perceive our children as a means of enriching greedy people. In the past, people have been breaking into our homes to take the child away from us. Luckily for us, she was not around but had visited a relative in the rural area. I have been in and out to various traditional healers for protection. They give us portions so that one could be invisible to the attackers. If you look at him today, he has strings around his waistline. I am a mother; no one wants to see their child being killed, let alone with some of the body parts missing. I will give all I have to see him live another day.

PWAs are killed, and their body parts are used as potions to make “Umuthi”. Thus, they are seen as means to acquire to an end, which is usually to make the other succeed in life. This was evident in one of the cases of the mother who was initially a participant in this study; however, had to pull out after the brutal murder of her child in early 2023. The child was four years old and was found near a riverbank with some of his body parts missing. It was later discovered that a sangoma instructed hitmen to kill the child and take some of the body parts so that his practice could flourish. The deceased child’s mother said, “No mother deserves to see their child like that. I do not see myself recovering from that. They sacrificed my 4-year-old so that a greedy man could become better?”

In February 2018, the 13-year-old Gabisile Shabane was abducted from her home. The 13-year-old Gabisile living with albinism. She was found almost a month after being missing. Her body was found in a shallow grave with some parts missing. It was later discovered that a sangoma sent the 28-year-old man arrested for her murder<sup>3</sup> to get body parts of any albino to make the 28-year-old man’s business flourish (ANA, 2018:1). Salewi 2011:10, has confirmed that PWAs constitute a vulnerable segment of society, they face the looming risk of extinction due to unabated killings rooted in the belief that elixirs derived from their body parts bestow luck, wealth, and prosperity without consequences.

## **Mothers face abandonment by their husbands**

As mentioned earlier, all the participants were either divorced or abandoned. Thembi, a 44-year-old mother from the North of KwaZulu-Natal, narrated her experiences since she gave birth to a child with albinism.

When my child was born, my husband and her family ordered me to leave my marital home because they believed the ancestors cursed me. They rained insults and called me all sorts of names, including a prostitute. They asked me to pack my belongings and leave the house. they mentioned that they had consulted a witch doctor (a sangoma) who had advised them. I had to relocate when my child was 10 to a place closer to the city center in the Eastern part of the province. The father of my child never looked at me the same. He always said that one day, he would kill me and this child of mine

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<sup>3</sup> A sangoma is the name for a traditional healer.

because it was clear that I had another relationship. After all, they have never seen something like “this” in his family. He thought I had an affair. He never looked at my son the same way he looked at his siblings (my other children). Every time he was drunk, he would come home and start shouting at how I cheated and brought “this” to his family. He called him “Ichilo,” which means a forbidden thing or thing that he curses. I was never comfortable with leaving my boy with him. If I had to attend to something in town, I would carry him on my back, cover him with a blanket, and take him to my mother’s house, about 5 kilometers away.

All the women mentioned that they had been accused of having an affair with white men or a tokoloshe<sup>4</sup> and that the women were punished for sleeping with the white man, and the child was the god’s way of exposing them. This same sentiment that a black woman sleeping with a white man will result in the birth of a child living with Albinism was reiterated by Barker et al. (2010:172). These sentiments by the communities reveal issues of ignorance and lack of trust for these women.

### **PWAs’ rights are compromised**

The rights of PWAs are compromised; all the participants reiterated this. For instance Thandeka, a 47-year mother, asserted that she has many fears because no one recognizes her child’s rights. She says she knows the child’s life will be taken away from her anytime. She added, “I don’t think the education department is doing anything to cater to PWA. My child has visual impairments due to the pigmented eye, and adding an irregular educational system lessens the chances of him being able to at least complete school because he cannot see the chalkboard”.

Another participant narrated a story of her uncle saying:

My uncle could not complete his education because he could not see clearly”. My greatest fear is that I have been formally employed, and this is because I could not complete my high school education. I fear the same for my child. I know the struggles of being unemployed. I know employers will not give him a chance, so I have prayed that God gives my son wisdom and persistence in all he does. The government should have a class in all the schools to cater

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<sup>4</sup> Generally, a tokoloshe is an animal used for Witchcrafts, which is usually sent to do evil to others.

to visually impaired learners. This will allow our children to be better people in the future. I am poor, and if something were to happen to me, I do not know what the future could hold for her child. I hardly see PWAs working in professional jobs, and the ones that you do see are because they came from well-off homes and were taken to private or semi-private schools. Where does this leave us? I am worried because one is nothing in life without education.

Joyful 40 years' mother also said that:

There are no working opportunities for PWA in this country. I fear that my child needs more working opportunities compared to other children. Besides the challenges that she is already faced with, she also needs to fight to get a better future. Every mother dream of seeing her children graduate and making something for their lives. I have anxiety about the unknown. I am taking my child to a private school for a better learning experience and to ensure she can attend university. I worry if my child will be able to be a doctor. Her dream is to become a Doctor, I sometimes look out to see if I find any Doctors living with albinism, and thus far, I have not seen any. What does this mean for my daughter? Does this mean that she could never be one?

The above narratives are difficult realities of discrimination, violence, and even death. This was one of the most difficult interviews. The social worker and counselor were always there to engage with the families before, during, and even afterward. People often broke down in tears and were there to take over and counsel the interviewees. They just want their stories to be out there so people can share their predicament and change their attitude towards them. The major issues raised concern life and well-being. It also foregrounds the important need for African communities to understand the plight of PWAs. This is where stakeholders, particularly the Christian community, become important, particularly its ministry to all the marginalized and dehumanized and its prophetic voice on behalf of these women and their families whose voices are not heard within the communities. In this light, the next section proceeds to reflect on the ethical and theological implications of the challenges facing PWAs.

## **Ethical and theological reflections on the challenges faced by people living with Albinism**

So far, the article has exposed major aspects of our socio-cultural beliefs that, until recently, have remained in the private realm. The first is our perception and understanding of people who are living with the condition of Albinism. Second is our sociocultural responses. These issues have yet to be fairly addressed sustainably, particularly in our religious circles. The vulnerability, discrimination, fear, and death of many people living with Albinism have forced these issues into the public agenda. However, many still face these challenges, as the participants' stories above have alluded to. The magnitude of the problem suggests the involvement of all stakeholders in the African communities, such as the governments, medical officers, chiefs, indunas, community leaders, and religious leaders, particularly churches, pay attention to the plight of women with children and family members living with Albinism. It seems that, as a church, we have been ill-equipped to deal with the moral complexities of sociocultural issues of this nature. Even though June 13<sup>th</sup> has been declared internationally as Albinism awareness, South Africa has chosen the month of September to observe National Awareness Month. People's attitudes towards PWAs have remained the same. The legacy of fear, secrecy, and taboo surrounding some beliefs and practices in the African culture has resulted in this crisis. Having interacted with the families of PWAs, we are convinced that the appropriate response to this crisis is for stakeholders in the community and the society at large to actively work towards a redemptive community and embrace those living with this condition. This is where the church is called upon to lead the discussions and deliberations. The Church's ethical and theological approach must first include the voices of families and the people living with the condition. Their experience should inform the course of action because, as noted above, they feel alienated from the community because of the socio-cultural constraints that frame their realities. Therefore, the ethical approach should deconstruct the myths and perceptions around families with people living with Albinism that influence their realities. Only when these myths and perceptions have been deconstructed will responding in any way to the challenges be a reality. In addition to deconstructing the myths, beliefs, and perceptions, the approach must help us reconstruct liberative narratives that enhance their humanity and dignity.

The many challenges they go through in the African communities call for a consequentialist approach to ethics which questions the right and wrong actions based on the consequence of the action itself. Brown (1995:41) says that “no act is to be judged as good or bad in itself, but its wrongness or goodness is dependent on the consequences of the action”. Thus, what determines right or wrong action depends on the consequences of the action. Looking at the consequences of the attitude and the actions of the communities towards families living with PWAs, through the lens of the ethical theory of consequentialism, the following issues emerge; the ignorance of our understanding of the condition of Albinism, justifying wrong actions in the name of culture, and undermining the rights and dignity of families particularly women living with children living with Albinism. The community’s attitude towards them is a moral and social injustice issue. However, like most community stakeholders, the church has remained silent about their plight. This neglect is what has informed the current chapter. This is because the consequential approach portrays God as the God of love, justice, and the voice to the voiceless, and the church is called upon to emulate. It calls for the church to be inclusive and to promote the dignity and humanity of the vulnerable, and in this case, families, particularly women with children living with Albinism.

Based on the narratives presented in this chapter, it is pertinent that the church pays attention to the plight of these women with children and family members living with Albinism so that they can be accepted, empowered, and equipped to live in their communities and have greater choices and not to be discriminated and judged. Being judgemental creates a divide between ‘us’ and ‘them’; we have noted that PWAs are viewed as “non-humans and ghosts” while those who are not are viewed as “humans.” The church should find ways of becoming the agent of change and transformation of the religio-cultural myths that expose PWAs to murder, abuse, and discrimination. Additionally, the church should create a safe space for families. In such a space, children living with Albinism should be free from any form of stigma to help them rediscover who they are in the face of their creator.

The fact that women are blamed and divorced for having children with Albinism suggests gender injustice in most African communities. Fighting against these injustices ought to be on the agenda of all congregations since the church is located even in the remotest part of Africa, where these myths and perceptions are prominent. Dominant masculini-

ties that perpetuate these myths and beliefs must be exposed and deconstructed. In responding to issues of gender inequalities in the African context, Ezra Chitando (2007:47) believes that the church needs to use the pulpit to challenge gender injustices due to dominant masculinity. He mentioned, “Sermons that challenge men to embrace gender justice must be preached with clarity and compassion.” In addition, he challenges the church to reach out to men in the places where they gather for leisure to engage with them on these serious issues; he challenges the church to be more open to new approaches to this kind of ministry (2007:47).

Another issue from the interview is the need for more knowledge surrounding Albinism; most African people are unaware of what albinism truly is (Masanja et al. 2014). We believe the church could join forces with the community leaders and the government to implement awareness campaigns to pass down knowledge about albinism. This can be done in community halls and churches. These campaigns must be led by mothers of children living with albinism. The church must extend its ministry to include traditional healers like sangomas. This is because they need to be taught that albinism is skin pigmentation and that nothing is magical about them. The issues about using the body parts of people with albinism start with the traditional healers and sangomas because they are the ones that send people to the community to attack people living with albinism. Referring to the story of Gabisile narrated above, it was reported that a traditional healer advised the man who killed the Gabisile Shabane to get the body parts of a person living with albinism so that he could flourish. As a result, sangomas must be educated about the condition because they greatly influence the killings and attacks of people living with Albinism. If the Church truly dedicates itself to comprehensive ministry, it would be imperative for the Church to establish a forum where open dialogues could occur between mothers of PWAs. The objective of these discussions would be to collaboratively devise practical remedies for dispelling the myths, beliefs, and misconceptions surrounding PWAs. Undertaking this approach would signify an understanding that mere identification of a moral quandary is insufficient without the concurrent provision of viable solutions, as articulated by Chirongoma (2006).

Another area of ministry is in the counseling of mothers because of their children’s conditions. Once mothers are fully aware of the nature of the disorder, it is important that the family also gets knowledge about it because sometimes a mother might happen to understand the disorder.

Still, the families cannot support the child because they see him/her, for example, as a “curse”.

For the church to carry out these tasks, bold prophetic leadership must speak out and bring God’s liberation and life to PWAs.

## Conclusion

This study was conducted in two cities, Pietermaritzburg and Johannesburg, respectively, with ten female-headed families living with albinism. It came out that the Lack of knowledge about this condition is the key reason why people with albinism suffer from social exclusion and live in constant fear of discrimination, abduction, rape, and murder. Even in their graves, their remains are exhumed for rituals. The stories of these women challenge the church to respond to the plight of PWAs. Most people see them as non-human objects for self-enrichment.

Considering this, the study has proposed a need for awareness campaigns to educate the community about this disorder. This is because the misconceptions about the disorder have led to myths and superstitions and the infringement and violation of the rights of people with albinism. The study challenges the church as an institution in most communities and calls for action. It needs to take the plight of PWAs seriously and be willing to advocate on their behalf.

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