A QualitativeStudy on Life Experiences of People with Albinism in Gaborone, Botswana

Abstract

It has been observed that, despite the efforts of various stakeholders to raise awareness on oculocutaneous albinism globally, regionally, and nationally and despite various studies surrounding the issue, stigma and marginalisation plague in many communities, including Botswana. The study seeks to explore the life experiences of people with albinism. It seeks such understanding through the direct testimony of people with albinism. In addition, the study will contribute to existing knowledge focusing on a disability that is more visible on the surface than its physical and mental limitations. Thus, it may contribute to awareness of what appearance means cross culturally and suggest ways in which the situation may be addressed and enhanced.

Introduction

The study explores the life experiences of people with albinism in Gaborone, Botswana and the misconceptions of societies towards people with albinism to appreciate people regardless of physical appearance. Derived from the Latin word 'albus' meaning 'white', oculocutaneous albinism (OCA) is a relatively rare genetic disorder in which the body does not normally biosynthesise melanin (McBride, 2014). Melanin is a photo protective protein whose role in the skin is to absorb ultraviolet (UV) light and prevent damage. Without melanin the skin is more prone to sunburn and skin cancer (McBride, 2014). In addition, lack of melanin results in a triad of signs which is pale skin, light hair, and pale iris colour. The condition is inherited in an autosomal recessive manner, which implies that the person with oculocutaneous albinism inherits two faulty genes, one from each parent. Both parents of the person with oculocutaneous albinism may appear unaffected but carry one faulty and one normal gene each (Winship, 2003; Christianson, Howson, & Modell, 2006).

Owing to the absence (or minimal production) of melanin, people with oculocutaneous albinism are affected by a variety of physical and physiological conditions, including marked sensitivity of the skin and increased risk of skin cancer caused through over-exposure to the sun. In addition, persons with oculocutaneous albinism may present with abnormal development of the optic nerve, which may result in poor vision (Winship 2003; Christianson et al. 2006). Although the person with oculocutaneous albinism has to cope with biological threats, the literature reveals that the major challenge faced by people with such a condition in most societies is stigma and prejudice from myths, superstition, and misinformation (Winship 2003; Christianson et al. 2006).

Ithas been observed that, despite the efforts of various stakeholders to raise awareness onoculocutaneous albinism globally, regionally, and nationally and despite various studies surrounding the issue, stigma and marginalisation plague in many communities, including Botswana. In this regard, Save the Children Research Report (2001) emphasises that stigma and discrimination have a significant impact on the self-image and self-respect of the individual concerned. This triggered the interest of the researchersto explore the life experiences of people with oculocutaneous albinism in Gaborone, Botswana.

Statement of the Problem

A study conducted by McBride (2014) revealed that in the UK, OCA is estimated to affect 3716 individuals (1 in 17 000 people) while the total population of individuals with OCA in Africa is unknown and its incidence will vary both between countries and within regions (McBride, 2014). In Tanzania, the OCA population is estimated at 31 345 (1 in 1429 people), which is nearly 8.5 times the UK OCA population. Zimbabwe has an OCA population similar to that of the UK, estimated at 3050 (1 in 4000–5000 people), but its total population is a quarter of that of the UK. In South Africa’s Venda region the incidence is 1 in 1970. Two clans with the same number of individuals with OCA have an incidence of 1 in 825 people in the Vhatavhatsindi clan and 1 in 3107 people in the Vhalaudzi clan (McBride, 2014).

Christianson, Howson &Modell(2006) report that oculocutaneous albinism is found globally but with a high prevalence in sub-Saharan Africa and in clusters in South America. Studies studies show that the condition is a global challenge requiring practical and comprehensive intervention (Pooe-Monyemore, Mavundla, & Christianson, 2012). In addition, some studies conducted on oculocutaneous albinism are not current, although their findings are significant for this study. For example, Kromberg, Castle, Zwane, and Jenkins (1989)research on oculocutaneous albinism in South Africa between 1982 and 1999, recording a prevalence rate of approximately 1 in 3 900 in Johannesburg, compared with 1 in 9 635 in Norway and Sweden (average number for both). The South African prevalence rate is higher than in other parts of Africa, such as Nigeria, where it has been reported to be 1 in 5 000 (Kromberg& Jenkins, 1982). Main (1987) drawingon the work of Kromberg (1982) discuss the high prevalence of albinism among the Southern Sotho peoples of whom the Tswana (the great majority of people in Botswana) are a part. In this group the prevalence is 1 in 2254, which is much higher than other comparable Southern African Bantu groups (for example, 1 in 4000 among the Xhosa, 1 in 9700 among the Pedi, and 1 in 28614 among the Shangaan) (Main, 1987).

However, there is lessliterature in Botswana about albinism and almost no attention has been paid to coping styles of those affected. Furthermore there has been even less research in the field of albinism in Botswana. Thus, the aim of the study is to explore in-depth knowledge of the life experiences of people with albinism. It seeks such understanding through the direct testimony of people with albinism. In addition, the study will contribute to existing knowledge focusing on a disability that is more visible on the surface than its physical and mental limitations. Thus it may contribute to awareness of what appearance means cross culturally and suggest ways in which the situation may be addressed and enhanced.

Literature Review

Albinism is a physical state but its effects are as much a result of social reactions to the condition as they are of the state itself. In Tswana traditional life there are many different customs and beliefs surrounding the causes and social treatment of people with albinism. Thuku(2011) states that, in most communities across the world, albinism is not clearly comprehended. Myths and misconceptions surround the condition.However this is amplified in sub-Saharan Africa largely because the light skin tone of PWAs stands out sharply in communities whose members are predominantly dark skinned. In some parts of sub-Saharan Africa, the condition was traditionally thought of as ‘a curse’ or as a form of ‘punishment’ from the gods or the ancestors for some wrongdoing of the parents. In other communities, it was thought that there was something wrong with the mother. For centuries, children born with albinism were routinely killed immediately after birth by parents and mid-wives and myths about albinism continue to persist in many parts of the continent (Thuku, 2011).

Furthermore there is evidence that people with albinism have negative experiences with members of their communities. Different scholars state that these include;prejudice, stigma based on superstition, myths, labelling, negative attitudes, fear of contagion, teasing, and being stared at.Thuku (2011) states that persons with albinism experience and continue to suffer stigma, prejudice, stereotyping, and discrimination in sub-Saharan Africa. It is a condition that cannot be hidden and, when a person with albinism is in a group of dark skinned people, he/she stands out as different. They are a visible minority and, in many parts of Africa, are subjected to open discrimination. The author observes that many women have experienced divorce and being shunned by their families after giving birth to children with albinism. They have been accused of sleeping with men of other races, of being cursed and unclean, and of being witches. In addition, children with albinism have also been hidden from the public, forbidden from socialising with others, and treated as outcasts.

In line with previous studies in Limpopo province (South Africa) by Kromberg 1992, Gaigher, Lund &Makuya2002, &Pooe- Monyemore 2003, community stigma and prejudice community are major challenges of most people with oculocutaneous albinism. The individuals felt socially stigmatisedon the basis of their skin colour, which is obvious owing to a lack of pigmentation. According to Link and Phelan (2001), stigma is associated with a deviation from what is normally expected. Nevertheless, Gaigher et al (2002) argue that the problems experienced by persons with oculocutaneous albinism do not necessarily relate to their obvious physical difference in terms of skin colour but to the social environment with which they have to cope, which is also clouded by communal myths and superstitions.

Small, (1998) in her paper Sociological Studies of People of Color with Albinism (1998) states that there isstigma attached to albinism and that, in general, it is equated to, and categorised as, a blemish, mark, stain, and even disfigurement. It is a visual stigma causing society to view it with suspicion and fear. Unlike any other stigma, albinism is the only condition mistaken for mixed race. People with albinism are also perceived to be less capable or having a character flaw. In Small's study, respondents stated that the community basically finds reasons to criticise and reject them. Astudy by Daniel (1989) on people with albinism in Nigeria, concluded that they suffer socially and psychologically due to family and society's negative attitudes.

The study byPooe-Monyemore (2012) found that myths and superstitions about oculocutaneous albinism affected the participants' everyday social life and self-image. The concernwas about the most common myth about people with oculocutaneous albinism that they "do not die naturally but simply disappear or vanish".

Kromberg (1992) found the myth to becommon amongst the South African black population, and suggests that it may be based on the distant past when people with oculocutaneous albinism were believed to be the offspring of a woman and a water spirit. The author is also of the opinion that a practical explanation for this myth could be that many people may not have seen individuals with oculocutaneous albinism pass on or die. Jordaan and Jordaan (1998) point out that beliefs in society affect people's attitudes to life, as well as behaviour in religious, ethical, political, and social spheres. Thuku (2011) argues that, due to misconceptions and myths, persons with albinism in many parts of Africa suffer from stigma and discrimination from birth and day- to-day lives, thus infringing antheir fundamental human rights and basic freedoms.

Myths associated with albinism in South Africa and Zimbabwe have a profound influence on the lives of people with the condition, from birth until death. The beliefs and superstitions surrounding the condition affect family life and interfere with access to education, employment, and marriage (Baker, Lund, Nyathi& Taylor, 2010). A woman with albinism in Zimbabwe commented, 'People think albinism is caused because the woman sexual contact with a tokolosh' (Baker, Lund, Nyathi, & Taylor, 2010:172). This is a very strong belief. At other times they think it is because she has sexual contact or impregnantedby a white man or because the parents have done something very bad and this is a punishment from the Almighty. The authors explained that the tokolosh is a malevolent spirit in Shona folklore which can be called upon to cause trouble for other people. Reflecting on this move from practical explanations to those founded on traditional beliefs, Bourdillon (1987) notes that anything out of the ordinary is considered by the Shona (originally from Zimbabwe) to have been caused by spirits angered by witchcraft or sorcery. Indeed, the birth of a child with albinism is often explained in such terms and the suggestion is that this is due to the influence of evil spirits. A local belief in the Venda region of South Africa is that the 'snake inside women' helps with the delivery of babies. The snake is considered to monitor and protect her pregnancy and it is only when the snake turns away that the pregnancy is left unprotected.

Thuku (2011) states that the use of derogatory names for persons with albinism has led to communities condemning them based on the condition and disregarding their humanity. In East Africa, most of the descriptive terms used to refer to persons with the condition are derogatory and demeaning. They suggest a lesser being. In Kiswahili, a language spoken by millions in the region, the name for persons with albinism is ZeruZeru meaning 'ghost-like creature' while others refer to them as 'mzungu' (meaning white person). While in some parts of the world the term 'albino' is accepted, it is increasingly seen as derogatory because it puts the condition ahead of the person. Old ways of describing people who are different have almost always been derogatory, therefore it is better to use 'person with albinism' than 'albino' (Small, 1998).

One common misconceptions about albinism is that it is contagious. Like people with leprosy or physical disabilities, people with albinism were traditionally segregated in much of Southern Africa. Today this continues as children with albinism are prevented from mixing with other children for fear of spreadingtheir'disease' (Baker, Lund, Nyathi, & Taylor, 2010). Some people refuse to shake hands with people with albinism, which is particularly problematic in certain circumstances, such as, at funerals where it is customary to shake hands as a sign of condolence. Others refuse to sit next to people with albinism on a bus or train and do not like to share taxis with them. A Zimbabwean with albinism sums up this attitude, 'Some people will not touch what I touch; in the bus no-one wants to sit near me, refuse to shake hands with, share utensils, touch or come near me' (Lund, 1998: 7). Some people with albinism even find their own family members avoiding direct contact with them (Onoja&Airahoubor, 2006:49).

Ntinda (2008) states that, in some parts of Africa, people with albinism are perceived as 'sacrificial lambs', from the biblical metaphor for someone or something that is sacrificed for the good of others. These individuals are wanted for their hands or genitals which are considered to be the body's strongest parts. People with albinism are hunted for this purpose as they are believed by some to possess supernatural or magical powers and if someone is married to an albino it is believed that they will be a very lucky man or woman (Ntinda, 2008).

Methodology

This study used a combination of research designs, which are exploratory and descriptive. This design allowed the study to be conducted in a completely natural and unchanged environment. In this regard, the researchers captured the role of social workers towards people with albinism through observation of communication during interviews. Therefore, the researchers had the opportunity to explorethe services for people with albinism and describe in more detail, filling in the missing parts and expanding understanding in this regard.

The study used a non-probability technique, namely the snowball technique. This encouraged participants to refer the researchers to other people in their social network, who contributed towards the study. The researchers requested the Chairperson of the Tshimologo Association of People with Albinism to help with identifying respondents and suggest other people who might be included in the study. This was done until the targeted sample size of fifteen (15) was reached. For this study, a sample size of fifteen respondents aged 21 to 50 years, one social worker, one employee from Office of the President (Disability Unit) and one philanthropist were selected. A sample size of not more than 30 participants is ideal for qualitative research as in-depth interviews are time consuming (Bailey, 2008).The study was cross-sectional, it was carried out at one point in time or over a short period.

Researchers incorporated document analysis, a form of qualitative research in which documents are interpreted by the researchers to give voice and meaning to an assessment topic. Documentary work involved reading a great deal of written material, however, little research has been conducted in Botswana regarding albinism and thus there are few materials from agencies or government departments to guide the interpretation of experiences encountered by people with albinism. Meanwhile, the researchers considered other studies conducted globally and regionally to interpret and analyse relevant data generated in different parts of the world.

During interviews, researchers utilized a code sheet to engage in data reduction. This method allowed the researchers to document responses in a form that could be more easily handled. It also allowed the researchers to have a column in which findings are discussed based on the literature review.

Results

Respondents in this study were asked to indicate their life experiences as people with albinism. Issues surrounding stigma and discrimination, myths associated with albinism, labelling and name calling, fear of contagion, teasing, being stared at, and unemployment are reviewed.

The findings of the study reveal that a majority of people with albinism experience stigma and discrimination in different locations. These include the communities in which they live, school, the workplace, hospitals and clinics, government offices, and different surroundings such as neighbourhoods, and towns. They stated that people stigmatise them and do not want to be associated with them because of their condition. One respondent described their experience thus:

> *"When I grew up, my family was ashamed of me and hid me from the community. My parents took me to the cattle post and did not want me to go to school. In my community they discriminated against me and I was not accepted hence giving my parents a good reason to*

> *keep me away from the community. People did not want to touch me and called me names such as (lelobo), and many times they would say this phrase when they saw me (lelobolelobofetolammala)" (cameloncamelon change colours).*

Another respondent buttressed this by stating that life is complicated by the way people treat them and there is a great deal of discrimination against those with albinism, Some individuals also believe horrible myths about them, such as, that they are not human and never die, that albinism is a curse from the gods, and that anyone who touches them will be cursed. The respondent further said:

> "*When I grew up, people did not want to interact with me and looked at me as if I was some kind of rubbish".*

Another lamented:

> *"I grew up in a very harsh and difficult situation. It was not easy especially at school. Children did not want to sit next to me and teachers did not take into consideration my sight problems as well as my slow pace. A few teachers made an effort to enlarge the font when writing notes on the board or printed notes for me while some did not care and used small font which was difficult to see. People did not want to be associated with me in any way and discriminated against me. They did not recognise me as a human being. My family and extended family have accepted me, I only experienced challenges with other community members who called me albino and looked down upon me. Neighbours during ceremonies such as weddings or funerals would not want me to touch food or peel any vegetables. It is common that, on such occasions, we offer help but in my encounters they did not want me to do activities such as cooking or slicing vegetables. Instead they would say I should wash the dishes or pick up litter".*

A majority of the respondents (15/16) indicated that it is very difficult building or having a bond with people generally, (particularly) teachers and other children at school. There is not much support and encouragement, especially from teachers.

In reaction to stigma and discrimination, respondents stated that they face harsh conditions as they grow up and are raised in a very difficult and discriminatory environment. They are denied leisure activities such as playing sport. Some are kept away from cities and hidden at cattle posts/fields as a way of protecting them from the discrimination that other people direct towards them. Some parents/families fail to accept them which leads to being hidden away from the community.

Discrimination by and against families including members with albinism

Findings regarding discrimination showed that some people with albinism are discriminated against by family and community members and some are abused because of their condition. Most respondents (14/16) reported that some people, especially those expecting or having given birth to children with albinism, kill them due to the pressure from other families and community members. Some communities tend to say or believe that a family with an individual with albinism is covered with a dark cloud or has been bewitched or attached by evil spirits.

One male responded:

> "*Yes, our families are still discriminated against because of perceptions that people are holding about albinism and families will not want to be associated with a family that has a member with albinism. Some say they do not want to be affected by the sins of that family"*.

Discrimination in urban and rural areas

According to responses regarding discrimination in cities and villages (11/16) respondents reported that growing up in rural areas as a person with albinism is not easy. It is much easier in towns as it possible to move from one point to another without being exposed or burnt by the sun because people use cars or combis.

One respondent said:

> *"Life in cities accommodates everyone because people mind their own business unlike in villages where there is much gossip among village members. The other time I went to some fields with my friend. From the bus stop we walked a very long distance to reach our destination and in the sun. I can imagine what people with albinism in rural areas go through and they experience that more often. I remember the very first time I went to town, when I applied for tertiary school. I did not know Gaborone very well at that time. I only knew Maruapula, where I stayed with a relative. Because I did not know how to move about in Gaborone, I had to ask for directions from people. The first person I asked for directions to Game City mall "gave me attitude" as well as the second person. They just looked at me as if I was some kind of rubbish. The third person was so impatient and felt I was wasting their time as they were in a rush. The fourth person gave me directions but distanced himself away from me. With those who gave me attitude, they continued to walk as if I was not talking to them. It was really obvious that they did not want to talk to me. Again, people in cities/towns seem to have little knowledge about albinism as compared to people in rural areas who are somehow stuck and still believe in cultural beliefs and certain myths about people with albinism. I remember the other time I was in Palapye volunteering and was part of an activity organised by Peace Corps USA. In this activity, the main aim was to bring together vulnerable children and teach them life skills. Some of the children who attended the training where from areas surrounding Molepolole and when they saw me they touched their belly buttom. From what I heard they did so because they have been told that if you see someone*

> *with my condition, they should touch their belly buttons so that they do not give birth to a person with albinism when they grow up".*

Overall, respondents stated that in towns/cities the lifestyle is fast, and people socialise and interact with only those close to them. With busy schedules and lifestyles, people tend to focus on their own issues unlike in rural areas where people are interested in other people's lives and gossip about them.

The remaining respondents (5/16) stated that life is better in the rural areas because of a smaller population which makes it easier to socialise and interact with the community. In cities, however, people stare too much and consider people with albinism as belonging in a totally different place. Even in shops there is too much staring which makes them uncomfortable.

Myths and superstitions regarding albinism

According to responses to the question of myths and superstition towards albinism, it was established that there are certain ideas that people still hold and that affect the respondents' everyday life. Most respondents expressed their concern about the most common myth that people with albinism do not die naturally but simply disappear or vanish. One female stated:

> *"There are myths that we make powerful, strong concoctions and that we have so much luck. Through such myths people with albinism are killed and this is hidden because there is a myth that says ga re sweranyelela (we do not die but disappear). In the past children were killed immediately as it was believed to be a curse and, when asked, families will just say mothoyoo o nyeletse (the person has disappeared)".*

In particular, majority of respondents indicated that problems they experience as people with albinism regarding their social environment (such as people surrounding them) is influenced by myths and superstition. In addition, another observation byrespondents was that the most common myths amongst the Batswana population was that they have powers to make one rich and they do not die, they vanish. They stated that it might be based on the distant past with albinism were belief that people with albinism are offspringsof parents (or a mother) being punished by God for their sins.

There was consensus amongst respondents that people still believe in myths regarding albinism. One of these is that, if someone touches a person with albinism, he/she will contract the condition. Another mythis that when one talks to a person with albinism he or she will give birth to a child with albinism. In addition, one respondent reported that it is believed that, if a person has sexual relations with a person with albinism, they will give birth to a child with albinism and when one shares food from the same dish with a person with albinism one will give birth to a child with the condition.

With respect to the issue of myths and superstitions towards people with albinism, respondents indicated that they fear for their lives as people might do anything to ascertain whether such beliefs are true.

One respondent stated that:

> *"Myths towards us are so intense; people believe that every part of our bodies has powers, from our hair and nails to other parts of the body (phekotsarona di bogalethata). However, I wonder if we had so much power as people with albinism, why wouldn't we use those powers to our advantage and make ourselves rich. That luck that people want from us, our body parts-why is it that we don't use them for our own benefit. We live in fear (re tshelajaakabommutla), we live in fear wondering what would happen to us because of what people think". "I walk every day from work to home, and when people offer me a ride, I ask myself questions whether it's a genuine ride or my life is in danger because of the beliefs they might have about us.*

In reaction to the issues of myths and superstition towards people with albinism, respondents stated that they have seen people spit saliva and touch their belly buttons, because it is believed thatthey will not give birth to a child with albinism. In addition, some people go down on their knees when they see people with albinism. However, all this is learned from the socialization/cultural beliefs.

Labelling and use of derogatory names

According to responses regarding labelling and name calling, a majority of respondents (14/16) mentioned that they are called names and labelled in a way that disregards their humanity. Commenting on the issue of labelling and name calling, one respondent said:

> *"People call us names such as albino, lekgoa, lechaene, and sepoko and It is not appropriate; the names somehow derogaory against us and make us feel like we are not human beings. It is better to say, 'person with albinism.' The names and labelling do not take into consideration that we are human beings as well. It is like they refer to an object or something else, and put our condition before humanity (baeteletsaboswafiko pee, mothokomorago)".*

Among the 14 respondents who did not tolerate the labelling and name calling, one reported:

> *"I grew up being called an albino and we were regarded as objects; we were undermined, and people perceived us as useless people who could not do anything. They believed we were neglected or punished by God. They did not see any potential in us, that's why they called us albinos and that to me showed lack of knowledge. Even the children, when they grew up, could differentiate between us and other people without albinism yet they looked at us as if we*

> *were objects. In some cases we were called white people and they would say we are not white people we are things called albinos. We grew up with that stigma, and not many understand our condition and that we are human beings. With time I managed to accept myself and started to interact and show people who called me albino that it was not appropriate".*

A feature that was also highlighted is that respondents mentioned that young children learn to label people with albinism because of the way they have been socialised and how the community perceives albinism.

Meanwhile, 2/16 respondents differed from others as they stated that they did not have any problem with being called names because they have learnt to accept the situation. One said:

> *"People call us names such as albino. The name is very weak and discriminatory. I feel it's better to say a person with albinism just as one can say a person with disability not disabled person. Not all people with albinism have accepted themselves and some are offended when referred to as an albino but I personally don't care much. In some instances, people will call one an albino not meaning to discriminate. With the self- esteem I have, I do not mind the word albino but when I grew up, I had no confidence and the word albino hurt me so much. The word albino does not show respect and it's not even polite. It takes courage for one to accept him/herself first and then the word will not hurt much".*

Another respondent remarked:

> *"I have no problem with being called an albino, I have learnt to accept the word. It also depends on how one uses the word. Some use it praising and some use it to belittle and look down upon us but I have learnt to live with it".*

Fear of contagion, teasing, and staring

Half of the respondents (9/16) expressed thatone common misconceptions about albinism is that it is contagious. They stated that wherever they go people make negative comments and some are afraid to stare at them. They further elaborated that some people refuse to shake hands with them whichis particularly problematic at a funeral where it is customary to shake hands as a sign of condolence. Others refuse to sit next to people with albinism on a bus and do not like to share taxis with them. One respondent summed up this attitude thus:

> *"Some people will not touch what I touch, even at weddings or funerals, and in the combis and taxis no-one wants to sit near me. It is that they can't say it but mostly their nonverbal communication says it all".*

In a nutshell, respondents reported that people refuse to shake hands, share utensils, touch, or come near them, and some people with albinism even find their own family members avoiding direct contact with them.

In summary, one respondent said:

> *"Some people say they get uncomfortable (basisimoga) when they see us. Even today some people cannot use the same cup or plate that has been used by a person with albinism or share a meal with us. At funerals and weddings, some people will not want us to assist in any way. At work, my supervisor once said I should not touch vegetables and fruits and some customers may not want to buy the products.*

Unemployment

A majority of respondents are faced with the challenge of unemployment, poor performance at school, and not having a Secondary Certificate is a serious challenge taking into consideration the limited employment opportunities in Botswana. They further reported that discrimination and faced negative attitudes limits their chances of employment because no one wants to hire a person with albinism even when they have the necessary skills. One female respondent said:

> *"The other time I was looking for a job and one of my relatives had a friend who was looking for a helper at home, so she recommended I work for the lady. My relative did not tell her friend that she had recommended someone with albinism and when I finally met with the lady who wanted a helper, she was shocked and told me that I could not work for her as she is afraid that her children will be afraid of me. Also, she has never interacted with someone of my condition, and I ended up not getting the job because of the condition."*

Discussion

The findings of the study reveal that a majority of people with albinism experience stigma and discrimination in different setting. These include the communities in which they live, schools, the workplace, hospitals and clinics, government offices, and different locations such as neighbourhoods and towns. This is supported by Thuku (2011) who stated that persons with albinism experience and continue to suffer stigma, prejudice, stereotyping, and discrimination. It is a condition that cannot be hidden and, when a person with albinism is in a group of dark-skinned people, he/she stands out as different. They are a visible minority and, in many parts of Africa, are subjected to open discrimination. They are shunned by their families and accused of being cursed, and unclean, and of being witches. In addition, the children with albinism are hidden from the public, forbidden from socialising with others, and treated as outcasts and is evident with some respondents.

The findings and literature for this study are constant with Maslow's hierarchy of needs. Maslow (1968) devised the hierarchical structure in which, he postulated that, generally lower-level needs have to be fulfilled before a person can reach the high level of self-actualisation. He further stated that a self-actualised person is someone who has already satisfied all the lower-level needs of safety, belonging, love, and respect. Like others, individuals with albinism need to go through these levels to be satisfied in life.

According to Felker (1974), all human beings want to 'belong' and every individual is born into social contextIf individuals lack other human beings around them to nurture them, they die. From Maslow's perspective, to belong means that an individual is part of a group and is accepted and valued by other members of that group. However, to belong requires a mutual sense of oneness. For self-esteem to be operative, it is not only necessary that the group regard individuals in this way but that individualsregard themselves as belonging. They must see themselves as accepted and valued members of the group. According to Maslow (1968), the need for safety, belongingness, love relations, and respect can be satisfied by other people.

With that said, people with albinism generally fail to reach the last stages of the pyramid. This is mainly due to the negative attitudes, discrimination, and stigma that is portrayed by different communities. Having physiological needs met does not necessarily mean that one is happy. People with albinism might have their physiological needs met but, as they progress to other stages that include the need for belonging and love and affection, relationships such as friendships, romantic attachments, and families help fulfil this need for companionship and acceptance, as well as involvement in social, community or religious groups. Because of different attitudes, these needs might not be met resulting in people with albinism not being able to reach self-actualisation. Without the love and a sense of belonging from the community, interaction and establishing relationships become a challenge for them. This makes it difficult to experience self-esteem, personal worth, social recognition, and accomplishment which leads to failing to gain recognition for accomplishments and having feelings of failure or inferiority.

Discrimination by and towards families including members with albinism

Findings regarding discrimination showed that some people with albinism are oppressed and discriminated against by family and community members and some are abused because of their condition. Most respondents (14/16) reported that some people, especially those expecting or having given birth to children with albinism, kill them due to the pressure and discrimination from other families and community members. Some communities tend to say or believe that a family with an individual with albinism is covered with a dark cloud or has evil spirits and has been bewitched.

This corresponds to the findings of Baker, Lund, Nyathi, & Taylor (2010) that families or mothers of people with albinism are discriminated against because it is believed that the woman has slept with a tokolosh. This is a very strong belief as the findings are consistent with those of Baker, Lund, Nyathi, & Taylor (2010) that it is because the mother has slept with a white man or because the parents have done something very bad, and this is a punishment from the Almighty. Therefore, people decide to distance themselves from those concerned. To support this, the social learning theory states that people can learn by watching other people perform the behaviour(Bandura, 1977). This suggests that some people may learn and adapt to this attitude and behaviour of discriminating against families and people with albinism.

Discrimination in urban and rural areas

The findings show that growing up is marginally better in urban than in rural areas. In towns/cities the lifestyle is fast, and people socialise and interact with only those close to them. With busy schedules and lifestyles, people tend to focus on their own issues yet in rural areas people are interested in other people's lives and gossip about them. In cities, however, people stare and consider people with albinism as belonging in a totally different place. Even in shops there is a great deal of staring which makes them uncomfortable. Bandura (1977) stated that, by observing the behaviours of others, people develop similar behaviours. After observing other's behaviour, people assimilate and imitate that behaviour, especially if their observational experiences are positive or include rewards related to the observed behaviour (Bandura, 1977). Therefore, the social learning theory states that people learn by observing, rehearsing and retention (Bandura, 1977). In this case, when other people stare or behave in a certain manner towards people with albinism, ultimately other people who have observed that behaviour will also portray the same behavior when they come into contact with people with albinism.

Myths and superstitions regarding albinism

The results show that there are certain myths and superstitions that people are still holding on to and these affect the respondents' everyday social life. A majority expressed their concern about the most common myths that people with albinism do not die naturally but simply vanish as well as that people with albinism have powers and luck.A few studies, such as that by Pooe-Monyemore (2012) found that myths and superstitions about albinism affected the participants' life and self-image. The most common myth was that people with albinism "do not die naturally but simply disappear or vanish". Nevertheless, Gaigher et al (2002) argue that the problems experienced by persons with albinism do not necessarily relate to their obvious physical difference in terms of skin colour but to the social environment which is also influenced by myths and superstition. On the other hand, Kromberg (1992) found the myth to be most common amongst the South African black population and suggests that it may be based on the distant past when people with albinism were believed to be the product of a woman and a water spirit.

Labelling and use of derogatory names

The study has shown that people with albinism are labelled and called names. A majority of respondents (14/16) mentioned that they are called names and labelled in a way that disregards their humanity. Commenting on the issue of labelling and name calling, they stated that people call them names such as albino, lekgoa, lechaene, sepoko which is not appropriate. The names make them feel that they are not human beings. The names and labelling do not take into consideration that they are human beings. They feel like objects and that their condition is given priority over their humanity.

Thuku (2011) confirmed that the use of derogatory names for persons with albinism has led to communities condemning them based on their condition and disregarding their humanity. In East Africa, most of the descriptive terms used to refer to persons with the condition are derogatory and demeaning. They seem to suggest a lesser being. In Kiswahili, a language spoken by millions in the region, the name for persons with albinism is ZeruZeru meaning ‘ghost-like creature’ while others refer to them as ‘mzungu’ (meaning white man). While in some parts of the world the term ‘albino’ is accepted, it is increasingly seen as derogatory because it puts the condition ahead of the person. Traditional ways of describing people who are different have almost always been derogatory, therefore it is better to use ‘person with albinism’ rather than ‘albino’ (Small, 1998).

However, the findings from the study and literature are supported by social learning theory. The principles of social learning are assumed to operate in the same way throughout life and observational learning may take place at any age. Social learning theory posits that people learn from one another, through observation, imitation, and modelling. Based on these general principles, learning can occur without a change in behaviour. The social learning theory states that people can learn by watching other people perform the behaviour. Observational learning explains the nature of children learning behaviours by watching the behaviour of the people around them and eventually imitating them.

Therefore, this suggests that children learn and adapt to the attitudes, beliefs and behavior (such as and name calling towards people with albinism) from the people around them being parents, family, and the community. The findings from the study showed that at times, when children come across people with albinism, they would say, “mother, there is a white person”, and the mother or parent mostly will respond by saying “it’s not a white person but an albino”. This explains that they observe how the people around them interact with and react towards people with albinism and imitate the behaviours observed.

Fear of contagion, teasing and staring

A study by Lund (1998) raised issues of fear of contagion. In the present study half of the respondents (8/16) stated that one of the most common misconceptions about albinism is that it is contagious. They said that wherever they go people make negative comments about them. They further elaborated that some people refuse to shake hands with them which can be particularly problematic in certain circumstances where it is customary to shake hands. Others refuse to sit next to people with albinism on a bus and do not like to share taxis with them. This was reinforced in a study Fazel (2012) where respondents stated: ‘When we get into taxis, people still move to the other side or even refuse to use that taxi. We are still calledisishawa (a Zulu word for a person who is cursed) and inkawu (an Nguni word for ‘white baboon’).Findings of the current study also revealed that some refuse to shake hands with people with albinism, which can be particularly problematic in at a funeral where it is customary to shake hands as a sign of condolence. Some people with albinism even find their own family members avoiding direct contact with them (Onoja&Airahoubor, 2006:49).

Unemployment

The results show that a majority of respondents are faced with the challenge of unemployment. Because of not doing well at school and most of them having Secondary Certificate is a serious challenge taking into consideration that there are no employment opportunities in Botswana. They further mentioned that being discriminated against and faced with negative attitudes limits their chances of employment because no one want to hire a person with albinism even when they have the skills.

Maslows’s hierarchy of needs explains that the lowest levels of the pyramid are made up of the most basic needs, while the more complex needs are located at the top of the pyramid. Needs at the bottom of the pyramid are basic physical requirements including the need for food, water, sleep, and warmth. Once these lower-level needs have been met, people can move on to the next level of needs which are for safety and security (Maslow, 2012). As people progress up the pyramid, needs become increasingly psychological and social. Soon, the needs for love, friendship, and intimacy become important. Further up the pyramid, the need for personal esteem and feelings of accomplishment take priority. Maslow emphasised the importance of self-actualisation, which is a process of growing and developing as a person to achieve individual potential.

However, it is difficult for people with albinism to reach their self-actualisation level. This is so because, in most cases they are not working because of lower qualification such as junior certificate and Cambridge certificate. Reason being the unconducive learning and also not taking into consideration their sight problems. Having said that, they fail to find job opportunities because of lower qualifications, stigma and discrimination against them. Because of not having employment opportunities, their basic needs are not met, thus making it difficult for them to move to the next levels such as feeling accepted, safe, and being secure. Not being able to move to the next level, destroys their esteem and confidence thus resulting in them not being able to establish friendships and intimacy which then leads to them not being able to integrate and socialise with other people. All this prevents the individual from reaching their self-actualisation. If their basic needs are met from the beginning it enables them to move on to the other levels, resulting in self-actualisation.

Limitations

The current study is exploratory thus it provides insights into experiences encountered by people with albinism. Secondly, Botswana is a large country as well as the city of Gaborone, thus the study sample was drawn from Gaborone and cannot be representative of all people with albinism in Botswana. Additionally, the sample size limits the generalizability of findings to the entire Gaborone.

Implications

The study has important implications for People with Albinism in Botswana and social assistance and protection in general. The present study indicated that people with albinism continue to be marginalized and not much has been done by social workers to assist and enhance the wellbeing of people with albinism. The study may help practitioners, such as social workers, counsellors, health workers, and teachers, and through them and through other means, community members, to understand the nature of albinism and the effects of negative behaviour/attitude towards those affected. The findings and recommendations are vital with regard to advocacy concerning design of interventions and implementation of programmes to address, reduce and prevent such stigmatization and discrimination. Human rights organizations may learn from the research the depth of suffering endured by those living with albinism (and their families) and translate the reviews/findings into self-help initiatives at community level.

Challenges and issues surrounding people with albinism are social issues, globally, regionally and locally, not only for individuals, groups, families and societies but also for policy makers. Therefore this study may give rise to the enactment of policies in the fields of health, education and human rights in general. Including people with albinism in health policies will take into consideration the fact that they have special needs regarding physical health. In addition, the study may also consider inclusion of young people with albinism in the education policy, with a focus on the challenges they face in the education arena.

Findings from this research may contribute to existing body of knowledge in many professional arenas, particularly education, with reference to experiences encountered by people with albinism during interaction with other community members. The study may point to the need for research that may be wider in scope and covering more geographical areas and different types of issues surrounding albinism. The study is significant in the sense that little research has been conducted in this field in Botswana. The research may also raise more questions and expose gaps that will require further investigation involving multi-disciplinary approaches and methodologies.

Conclusion

The study explored the life experiences of people with albinism in Gaborone. The study show that albinism is still, both socially and medically profoundly misunderstood. The physical appearance of persons with albinism is often the object of erroneous beliefs and myths (influenced by superstition) which foster their marginalisation and social exclusion. The findings revealed that people with albinism experience challenges such as stigma, discrimination and prejudice. This extends to their families in urban and rural areas. Furthermore, myths and superstition are associated with albinism, as are labelling and use of derogatory names, negative attitudes, fear of contagion, teasing and staring, and unemployment. In conclusion, the study allowed the voices of a group of persons with albinism to be heard and the message that came across strongly was the need to enhance knowledge and awareness of the condition. In the result a humane and caring society would be created in which the rights of all groups are respected, including those with albinism.

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