



Myths Surrounding Albinism and Struggles of Persons with Albinism to Achieve Human Rights in Yaoundé, Cameroon

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Abstract

Persons with albinism (PWA) in Yaoundé, Cameroon are reported to experience stigma, discrimination and violation of their human rights based primarily on their lack of pigmentation in their skin, eyes and hair. This study explores the challenges faced by persons with albinism, with particular reference to their knowledge of albinism, social and health issues and support. This qualitative research study recruited persons with albinism through a non-probability sampling technique in the city of Yaoundé, capital city of Cameroon. Data were collected through three focus group discussions with 19 persons (13 women and 6 men, adults) with albinism and thematic content analysis was employed to analyze responses. Almost all participants revealed societal discrimination, stigmatization, human rights violations, and some reported frustration due to injustice, rejection and superstitions. All the participants had visual problems and 12 had skin diseases. These conditions were inadequately managed due to lack of care, rejection by others, superstition and limited financial resources. The majority of participants had a good understanding of albinism. This study urges social work interventions such as support groups for persons with albinism and their families; educational awareness programmes; and advocacy for the rights of persons with albinism to healthcare, education and employment opportunities, and to demystify all myths and cultural beliefs surrounding albinism.

Keywords People with albinism · Discrimination · Minority group rights · Lack of care · Cameroon

Introduction

Albinism encompasses a group of inherited disorders of melanin synthesis, the pigment that protects the skin from ultraviolet (UV) light from the sun. Persons with albinism (PWA) may lack pigmentation in the skin, eyes and hair which is referred to as oculocutaneous albinism (Nasr 2010). Oculocutaneous albinism (OCA) may cause visual impairment due to hypopigmentation of the iris and retina, hypoplastic fovea, hyperopia, strabismus, photophobia, loss of stereoscopic

perception and nystagmus (Eballé et al. 2013; Simona 2004). This visual handicap significantly hampers their educational performance because they cannot read nor see the blackboard well. It also causes irreversible skin pathology such as skin cancer due to the lack of melanin that protects the skin against ultraviolet (Aquaron 1990; Kromberg et al. 1989).

Oculocutaneous albinism (OCA) is prevalent among indigenous people in Africa. The precise prevalence of albinism in the human race is not clear but estimates say that the ratio is about 1 in 17,000 (Wiete 2011). The estimates of the prevalence of albinism in Africa range from 1 in 5000 to 1 in 15,000 (Phatoli et al. 2015). It is obvious that the condition is more noticeable in Africa and thus also spurs more moral misconceptions in society (Hong et al. 2006).

Albinism Myths and Misconceptions

The difference in skin creates adaptation and socialisation problems, with many myths and misconceptions surrounding PWA that have spread over the years within many African communities for diverse reasons (Scheen 2009; Thuku 2011). Views from Zimbabwe and Tanzania on the ritual

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murder and raping context revealed that albinism was believed to bring good health, financial and material wealth, cure HIV/AIDS and can appease the gods of the mountain when a volcano starts to erupt (British Broadcasting Corporation 2007, 2008; Roura et al. 2010; Machoko 2013). In addition, the study by Deborah et al. (2010) in Tanzania revealed that miners use the bones of persons with albinism as amulets or bury them where they are drilling for gold, and that fishermen weave the hair of persons with albinism into their nets to improve their catches. Furthermore studies conducted by Bieker (2006) and Braathen and Ingstad (2006) in Tanzania and Malawi (Braathen and Ingstad 2006) respectively reported that people with albinism are perceived as ghosts and cannot die but instead disappear, - the reason why they are perceived as being mysterious and dangerous beings. In South Africa, Fazel (2012) reported that when people with albinism get into a taxi, people still move to the other side or even refuse to use that taxi. Persons with albinism deserve to have their rights to life and security protected, as well as the right not to be subjected to torture and ill treatment. The above cited myths reported across Africa imply that stigmatisation of people with albinism is still very common in the region despite the United Nations Human Rights Council and the African Commission on Human and Peoples' Rights adopted resolutions calling for the prevention of attacks and discrimination against persons with albinism. Few studies have been conducted in Central Africa especially Cameroon to establish some of the challenges faced by PWA.

Aim of the Study

The study aimed to explore the challenges faced by persons with albinism, with particular reference to their knowledge of albinism, social and health issues and support.

Method

Study Population

The present study used a qualitative research design in which data were collected from 19 people with albinism through non-probability sampling in the capital city of Yaoundé, Cameroon. The research tools included three focus group discussions (FGD), each group made of 6 to 7 adults with albinism grouped according to their availability to take part in the focus group. Both men and women aged 18 years and above living in Yaoundé were invited to participate in this study. Guidelines for the FGD were developed based on previous studies and literatures about albinism (Wiete 2011; Scheen 2009; Deborah et al. 2010) by the research team, which included both the theoretical and practical sessions on qualitative interviewing with an emphasis on the 'funnel approach' in

which interviews start with broad questions and were progressively tailored to focus on specific issues spontaneously raised by interviewees. The research team consisted of native public health expert researchers specialised in qualitative research methodology.

Setting

This study was carried out from February to March 2015 in Yaoundé, the capital city of Cameroon and located in the Centre Region. The city was chosen because it is a cosmopolitan region and easy to find PWA originating from different regions of the country and to reveal representative myths and challenges that PWA faced in Cameroon. The focus group discussions were conducted in a conference hall accessible by all participants.

Data Collection

The recruitment of the participants (13 women and 6 men) was done through a non-probability purposive sampling. We approached an Albinos' Association in Cameroon and explained to them our goal of recruiting their members for our study. An interview guide with open questions on the people with albinism's knowledge of the albinism, psychological and social issues and medical/health issues was used to discuss with participants. The interview guide questions were developed by the research team with the aim of overcoming the limits of the previous surveys carried out on people with albinism (Wiete 2011; Deborah et al. 2010). The interview guide was pre-tested to ensure that the questions were well understood. The FGDs took about 60 min to be performed per group. The authors carry out the FGDs. Background information was also collected. Participants were interviewed in French or English until redundancy when both the participants and researchers felt that no more information could be obtained.

Data Analysis

All the FGDs were recorded, transcribed and translated into English before analysis. Thematic content analysis process was used to analyse data as defined by Grinnell and Unrau (2011) with the aim of exploring the challenges faced by person with albinism. Each FGD was transcribed verbatim by the authors themselves in order to secure the details relevant to the study analysis. Each FGD transcript was about 30 pages. Firstly, we read through the interview in detail, followed by analysing the text line after line in search of meaning units, at the same time starting with the open coding process to understand the meaning of the text. Secondly, codes from all the interviews were compared to develop categories to capture the manifest meaning. Thirdly, themes were developed to provide

understanding of the more latent meaning and finally, proper cross-checking was done by the research team.

Trustworthiness

Informants with different backgrounds and social settings increase the credibility of the study. An open-minded approach and a well-prepared interview guide were used to keep pre-understanding in brackets to explore and find new knowledge. The trustworthiness of the analytical process was strengthened by the joint work of the authors, where repeated discussions based on our different cultural backgrounds improved reflexivity throughout the research process. Peer debriefing by presenting our findings to some participants was done. Findings are reinforced by informants’ quotations.

Ethical Considerations

Ethical clearance was obtained from the National Ethics Committee for Human Health Research and ethical permission was granted by the Cameroon Ministry of Public Health through the Centre Regional Delegation of Public Health (No. 2016/12/852/CE/CNRS/SP). Both verbal and written consent were obtained from the participants before the focus group discussions were held. Counselling was offered to participants if needed. Indirect benefits involved the enhancement of knowledge gained from the study. The recruitment of participants was voluntary and they were reminded of their complete right to withdraw from the study at any point in time without the any explanation before the publication of the results. All information collected from participants was kept confidential and with no trace of identification details found in the final report.

Data Availability Data is attached with the manuscript.

Results

Socio-demographic Characteristic of Participants

A total of 19 persons with albinism participated in the focus group discussion with a mean age of 31 ± 11.8 years. The age range of these participants was from 18 to 52 with majority of the participants below 40 years of age. More than two-thirds of participants were females. Although all the participants recruited were residents of Yaoundé, the capital of Cameroon, they originated from five out of ten regions of Cameroon. Almost two-thirds of these participants had secondary education with only four of the participants being holders of university education. More than half of the participants were single and three were married. Table 1 reports the socio-demographic characteristics of participants.

Five themes that emerged from our data analysis are as follows: superstitions and rejections by others; frustrations, discrimination, stigmatisation and injustice; struggling for economic autonomy and call for improvement of their right and justice; burden of health problems, lack of care and mistrust; good knowledge about albinism.

Superstitions and Rejection by Others

Most of the participants expressed that they have experienced rejection in their family, society, job/work recruitment/at work and school. People thought that they were monsters or witches, and insulted, laugh and beat them. One participant revealed that she was rejected by her mother because she was a person with albinism. The mother was even advised to kill her when she was born. People refused to sit close to them because they were afraid and one said that PWA has always been perceived as abnormal human beings or ghost. A woman said that

My childhood was very sad because my mother was afraid, she didn’t accept me and she compared me to other children.

Some people think that they bring luck and use their hair or nails to get luck or spiritual power or for other spiritual

Table 1 Socio-demographic characteristics of sample (N = 19)

Characteristics	Frequency (number)	Percentage
Sex (N = 19)		
Male	6	31.6
Female	13	68.4
Age (in years) (N = 19)		
18–30	11	57.9
31–52	8	42.1
Region of origin (N = 19)		
Centre	11	57.9
West	4	21.0
North West	2	10.5
Littoral	1	5.3
East	1	5.3
Marital status (N = 19)		
Single	16	84.2
Married	3	15.8
Level of educational (N = 19)		
Primary	1	5.3
Secondary	14	73.7
University	4	21.0

activities. To get a job was not easy because employers thought that they were not competent. A woman stressed that other children compared her to a witch and that in the school they would ask her why her hair or head was different and others were afraid of her. If she drank from a cup, they would not drink from the same cup anymore. In addition, one of the participants said that the doctor who took care of the mother during delivery told the mother that she had given birth to a monster.

Frustrations, Discriminations, Stigmatisation and Injustice

Almost all participants revealed societal discrimination because of their skin colour and this negatively affected their self-esteem but made them strong and self-confident. A woman expressed that she was harassed when she was a child and people would call her names. Frustration was exacerbated by the fact that because of discrimination, they cannot find a job because of vision problem and albinism condition. They were told in the family and society that they were different from others or that they cannot eat all foods. A woman said that her family told her

‘eat this, don’t eat this’ or that you are different from others.... saying certain words, then you start realising that you are not like others.

Twelve participants reported that their rights to education and healthcare were compromised. They seldom got support from the teachers or friends in school when they could not read because of visual problem. Besides this, they did not get glasses from health care to enable them see well. People ignored the fact that they could not see during classes and instead accused them of being lazy. Some failed the exam because of this problem or were not motivated to go to school. Lives of some were threatened as revealed by a woman whose mother was advised to kill her when she was born. A participant stressed that albinos are rejected because people wonder

‘why are you white and am I black?’ and attribute it to witchcraft and say that it is mystical.

Many felt lonely because they were isolated from the community and in school, classmates did not want to sit close to them or to drink in the same cup. But besides this, many were supported by their parents, grandmothers, some friends and family members. Some teachers were supportive, but not all. A woman revealed that her

teacher was supportive and said to her that you didn’t come to school to meet people, but to study.

Frustration was also related to lack of employment and poor/lack of education. A man said that he was denied a military job because of visual problems and the colour of his skin. Another participant said that she was not accepted for a job because they said that she was not *competent*. Participants stressed that

we are not the cause of our frustration, it is the society who makes our situation frustrating which is in line with the social model of disability.

They said that the state did not support them in case of health problem and that three PWA died recently from skin cancer without getting help either from the state or non-governmental organisations.

Struggling for Economic Autonomy, Call for Improvement of Rights and Justice

All participants claimed that they wanted to create their own job in order to be independent and autonomous. They wanted to have good education and self-employment to avoid discrimination at job sites. They also requested for the government policy makers to increase character font size in school examination scripts and provision of eye glasses to PWA to enable them read. Moreover, they stressed that media should be involved in educating the public to respect and treat people with albinism as normal human beings. They called on the government to reinforce the United Nations Human Rights Council’s resolutions on Human and Peoples’ Rights calling for the prevention of attacks and discrimination against persons with albinism. Specifically, they craved justice because they were always disqualified whenever they competed/applied for a job. Moreover, they craved more information to educate their families and society about their condition.

Burden of Health Problems, Lack of Care and Mistrust

All the participants had visual problems which was mostly myopia or short-sightedness, implying majority of the participants could see near objects but not far objects. Most of the participants reported to have skin diseases but lacked appropriate health intervention. Health problems were exacerbated because of unaffordable health and lack of social care. Some participants stressed the fact they have resorted to preventive measures through the wearing of appropriate dresses to protect their body from sunlight since they cannot even afford to use sun protection cream or sunscreen.

Good Knowledge About Albinism

The knowledge of albinism among PWA was assessed using two main questions and results showed that 5 out of 19 participants reported that albinism was a genetically inherited

disorder while 11 of the participants perceived it as the dysfunction or absence of melanin. A woman described the myth that an albino baby can either be got from the mating of an African-black and a ‘métisse’ (means a child got from an African black and a European white colour skin parents):

It can be hereditary or not... My grandmother was a ‘métisse’ that has given rise to a person with albinism...but we never had any history of a person with albinism in my family. Due to this, we suspected that we might be from the crossing of a métisse and a black man.

Discussion

The current study revealed that the majority of the participants had good knowledge of albinism, contrary to a study conducted by Lund and Gaigher (2001) in South Africa that revealed that just 11% of participants could attribute their pale skin colour to lack of pigments, inheritance and something wrong with their genes. One reason for the difference in knowledge of albinism among participants might be due to the age difference between participants in the studies. In the current study, adults (18–52 years) were interviewed as compared to the Lund and Gaigher study (2001) whose participants were both children and adults (9–21 years of age). Another reason is the strong desire by our participants to get more information about their status by themselves in the present study.

All our participants had visual problems, which was mostly a decrease in visual acuity. These findings concurred with previous studies conducted by Eballé et al. (2013) and Maia et al. (2015) among PWA in Cameroon and Brazil respectively, which revealed that low vision combined with skin lesions and social stigma may contribute to disturbances in the quality of life of oculocutaneous albinos. The lack of retinal pigment required for the normal development of the visual system leads to the lifelong ocular problems that are always associated with this disease including disabling sensitivity to bright light and glare, involuntary eye movement, lack of binocular vision and large refractive error (Biswas and Lloyd 1999).

The majority (Braathen and Ingstad 2006) of our participants reported having skin diseases and lacking appropriate healthcare intervention. Thus, most participants have resorted to preventive measures through the wearing of appropriate dresses to protect their body from sunlight since they cannot even afford to use skin cream. This observation is in keeping with other African studies (Luande et al. 1985; Lund and Gaigher 2001; Mabula et al. 2012; Mosima 2016). Skin cancers are the most common cancers among people with albinism in our environment because sunscreen for the

oversensitive skin is rarely available (Luande et al. 1985; Mabula et al. 2012). Albinism and exposure to ultraviolet light appears to be the most important risk factor in the development of these cancers. Late presentation and failure to complete treatment due to financial difficulties and lack of radiotherapy services are the major challenges in the care of these patients (Mengnjo 2016). The possible reason for the skin problems is due to the lack of a protective skin pigment that leads to increase in skin ailments from the young age, with photoageing, lesion and non-melanoma skin cancers (Aqaron 1990; Kromberg et al. 1989).

Participants experienced rejection, harassment, frustration, violence, abuse and loneliness in society, school, workplaces and even in their families. This is not different from a study carried out among school children in Zimbabwe (Lund and Gaigher 2001). Lund revealed that the children living with albinism were also subjected to humiliation through the calling of names, treated as misfits or outcasts, refusal to sit, eat, play and even beaten by their peers. Their poor health and social condition makes PWA especially vulnerable to poverty, as they tend to be less educated than the rest of the population (McBride and Leppard 2002).

The job discrimination reported by the participants has oriented them towards self-job creation and self-employment. Many employers see them as incompetent and unproductive employees with many limitations such as reduced vision and fragile health status. Similar results were also reported by Bieker (2006), who found that people with albinism in Tanzania are commonly considered to be lazy, as they hardly ever work their fields during midday like others but prefer the hours around sunset and sunrise to protect their skin. Thus, the education of the general public through the media will go a long way to solve this problem and improve on the self-image and health status of those living with this condition. The increasing of font sizes in examination scripts, to address the medical concerns of this population through the provision of affordable health and the offering of start-up grants to PWA to create their own employments were the urgent needs expressed by the participants that could enable them cope better in the society.

Our findings can be applicable to other countries with the same characteristics but, further analysis of this situation of people with albinism should be done quantitatively using a larger population size.

Conclusions

People with albinism in this study faced enormous social challenges such as discrimination, rejection and stigmatisation ranging from the family to the societal level. The majority of participants had visual and skin problem; however, these conditions were inadequately managed due to limited financial

resources, neglect and lack of care. This study urges social work interventions such as support groups for persons with albinism and their families; educational awareness programmes; and advocacy for the rights of persons with albinism to healthcare, education and employment opportunities. Conclusively, the involvement of persons with albinism in drafting policies would greatly ameliorate their living conditions and rights.

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Compliance with Ethical Standards

Competing Interests The authors declare that they have no competing interests.

References

- Aquaron, R. (1990). Oculocutaneous albinism in Cameroon: a 15-years follow-up study. *Ophthalmic Paediatrics and Genetics*, 4, 255–263.
- Bieker, F. (2006). Lebenssituationen von Menschen mit Albinismus in Lushoto (Tanzania): Ethnographie und vergleichende Analyse. Unpublished Magister-Thesis at the Freie University, Berlin, Germany.
- Biswas, S., & Lloyd, I. C. (1999). Oculocutaneous albinism. *Archives of Disease in Childhood*, 80, 565–569.
- Braathen, S. H., & Ingstad, B. (2006). Albinism in Malawi: knowledge and beliefs from an African setting. *Disability & Society*, 21(6), 599–611.
- British Broadcasting Corporation (2007). Tanzania fear over albino killing. <http://news.bbc.co.uk/2/hi/africa/7148673.stm>.
- British Broadcasting Corporation (2008). In hiding for exposing Tanzania witchdoctors. <http://news.bbc.co.uk/2/hi/africa/7523796.stm>.
- Deborah, F. B., Jesper, B. J., & Richard, S. (2010). Miner's magic: artisanal mining, the albino fetish and murder in Tanzania. *Journal of Modern African Studies*, 48, 369.
- Eballé, A. O., Mvogo, C. E., Noche, C., Zoua, M. E. A., & Dohvoma, A. V. (2013). Refractive errors in Cameroonians diagnosed with complete oculocutaneous albinism. *Clinical Ophthalmology*, 7, 1491–1495.
- Fazel, A. (2012). Albinos “lonely call for recognition”. Mail & Guardian Health Supplement. 1.18–24 May.
- Grinnell, R. M., & Unrau, Y. A. (2011). *Social work research and evaluation: foundations of evidence-based practice*. 9th edn. Oxford: Oxford University Press.
- Hong, E. S., Zeeb, H., & Repacholi, M. H. (2006). Albinism in Africa as a public health issue. *BMC Public Health*, 6, 212.
- Kromberg, J. G. R., Castle, D., Zwane, E. M., & Jenkins, T. (1989). Albinism and skin cancer in Southern Africa. *Clinical Genetics*, 36, 43–52.
- Luande, J., Henschke, C. I., & Mohammed, N. (1985). The Tanzanian human albino skin: natural history. *Cancer*, 55, 1823–1828.
- Lund, P. M., & Gaigher, R. (2001). A health intervention programme for children with albinism at a special school in South Africa. *Health Education Research*, 17(3), 365–372.
- Mabula, J. B., Chalya, P. L., Mchembe, M. D., Jaka, H., Giiti, G., Rambau, P., Masalu, N., Kamugisha, E., Robert, S., & Gilyoma, J. M. (2012). Skin cancers among albinos at a university teaching hospital in northwestern Tanzania: a retrospective review of 64 cases. *BMC Dermatology*, 12, 5.
- Machoko, C. G. (2013). Albinism: a life of ambiguity—a Zimbabwean experience. *African Identities*, 11(3), 318–333.
- Maia, M., Volpini, B. M. F., Santos, G. A., & Rujula, M. J. P. (2015). Quality of life in patients with oculocutaneous albinism. *Anais Brasileiros de Dermatologia*, 90(4), 513–517.
- McBride, S. R., & Leppard, B. J. (2002). Attitudes and beliefs of an albino population toward sun avoidance. Advice and services provided by an outreach albino Clinic in Tanzania. *Archives of Dermatology*, 138(5), 629–632.
- Mengnjo, M. E. (2016). Most albinos die because of lack of treatment-president. Cameroon Post. From: <http://www.cameroonpostline.com/most-albinos-die-because-of-lack-of-treatment-president/>
- Mosima E. (2016). Cameroon: albinism-sunlight, major enemy. The 2016 edition of the World Albinism Day was celebrated in Cameroon. Cameroon Tribute. From: <http://allafrica.com/stories/201606150816.html>
- Nasr, S. L. (2010). How albinism works. <http://health.howstuffworks.com/skin-care/problems/medical/albinism.htm/printable>.
- Phatoli, R., Bila, N., & Ross, E. (2015). Being black in a white skin: beliefs and stereotypes around albinism at a South African university. *African Journal of Disability*, 4, 1–10.
- Roura, M., Nsigaye, R., Nhandi, B., Wamoyi, J., Busza, J., Urassa, M., Todd, J., & Zaba, B. (2010). Driving the devil away: qualitative insights into miraculous cures for AIDS in a rural Tanzanian ward. *BMC Public Health*, 10, 427.
- Scheen, T. (2009). Mordaus Aberglauben. <http://www.faz.net/s/RubDDBDABB9457A437BA85A49C26FB23A0/Doc~E00F49AAE85614AE9B604096366C417D7~ATpl~Ecommon~Scontent.html>. Accessed 10 July 2017.
- Simona, B. E. (2004). Albinos in black Africa. *International Journal of Dermatology*, 43, 618e21.
- Thuku, M. (2011). Myths discrimination and the call for special rights for persons with albinism in Sub-Saharan Africa, at: www.underthesamesun.com/%2F%2FMYTHS.F.&hl=enZA&qsubs=1427930374208.
- Wiete, W. (2011). Life of albinos in East Africa threatened: a most bizarre and dramatic consequence of having a skin colour disease. 2011, <http://colorfoundation.org/accessible>.