

Factors Affecting Quality of Life for People Living with Albinism in Botswana



Ellen E. Anshelevich, BA^a, Karen I. Mosojane, MBBS^b,
Lorato Kenosi, MSocSci^c,
Oathokwa Nkomazana, MB ChB, FCOpt (SA), MSc, PhD^d,
Victoria L. Williams, MD^{b,e,*},¹

KEYWORDS

- Oculocutaneous albinism • Albinism • Quality of life • Botswana • Health care access • Stigma
- Discrimination • Disability rights

KEY POINTS

- Similar to populations with oculocutaneous albinism (OCA) in other regions, our cohort in Botswana faced difficulties obtaining equal rights to physical, psychosocial, and environmental health, contributing to lower quality of life (QOL).
- Skin health and visual impairment concerns, along with limited access to health care, created physical barriers to health for people with albinism (PWA) in Botswana.
- Psychosocial health was impacted by pervasive stigma and discrimination, along with myths and superstitions about albinism; these impeded social interactions and psychological functioning with negative emotions and thought/behavior patterns.
- Barriers to the successful personal development of education and employment, fears for safety, financial insecurity, and disability rights concerns created barriers to environmental health for PWA.
- PWA need disability rights protections to guarantee access to skin and visual health, equal opportunity for personal development, access to governmental support programs, and social inclusion to improve their overall QOL.

INTRODUCTION

Oculocutaneous albinism (OCA) is an autosomal-recessive disorder characterized by lack of melanin production in the skin, hair, and eyes.^{1–8} Melanin is a pigment that absorbs ultraviolet light; hence people living with albinism (PWA) lack photoprotection and are more vulnerable to photodamage and skin cancers.^{1,2,4,6–9} Because melanin-producing cells are critical for visual

pathway development, all PWA have some level of visual dysfunction, which commonly includes nystagmus, strabismus, photophobia, and reduced visual acuity.^{1,8}

The worldwide prevalence of the disease is approximately 1 in 17,000 births, with about 1 out of every 70 people carrying a gene for OCA.^{1,2,8} However, OCA is more common in Africa, with prevalence rates of 1 in every 1000 births in some areas.^{2,6,8,10} The risk of squamous cell

^a Department of Dermatology, Perelman School of Medicine at the University of Pennsylvania, 2 Maloney Building, 3600 Spruce St, Philadelphia, PA 19104, USA; ^b Ministry of Health, Gaborone and Wellness, Headquarters, Private Bag 0038, Botswana; ^c Faculty of Social Sciences, Department of Psychology, University of Botswana, 4775 Notwane Rd, Gaborone, Botswana; ^d Faculty of Medicine, University of Botswana, 4775 Notwane Rd, Gaborone, Botswana; ^e Perelman School of Medicine at the University of Pennsylvania, 3737 Market Street, Philadelphia, PA 19104, USA

¹ Indicates a previous affiliation when this research was conducted.

* Corresponding author. 2 Maloney Building, 3600 Spruce St, Philadelphia, PA 19104, USA.

E-mail address: tori22@gmail.com

Dermatol Clin 39 (2021) 129–145

<https://doi.org/10.1016/j.det.2020.08.012>

0733-8635/21/© 2020 Elsevier Inc. All rights reserved.

carcinoma (SCC) has been reported as high as 1000 times greater in PWA in Africa than in the general population, and PWA are often diagnosed at advanced stages.^{4,11} Reports have indicated that various social factors, such as poverty, low health care access, and limited knowledge about albinism, leave PWA vulnerable to higher rates of skin cancer and poorer outcomes.^{2-4,7,11-14} Additionally, PWA in Africa face deeply embedded stigma, discrimination, and social marginalization, which can compound their health risks and affect quality of life (QOL).^{2,7,9,15,16} A challenge unique to PWA in Africa is the widespread myths/superstitions that can drive persecution and murder of PWA for their body parts, which are used as talismans in African traditional medicine.^{3,9}

QOL is defined as an individual's perception of their life in the context of their culture and value systems.^{17,18} The World Health Organization (WHO) has emphasized the importance of QOL by defining health as the absence of disease along with a positive QOL.¹⁷ QOL is strongly influenced by factors in an individual's physical, psychological, and sociocultural environments.^{7,9,19} Assessing QOL is important for measuring the impact of disease on daily life to inform patient management and policy decisions.^{16,18,20} Few studies have specifically investigated QOL for PWA, and thus far, poor health and social stigma are reported to detrimentally affect PWA in South Africa, Zimbabwe, Tanzania, Nigeria, and Brazil.^{5,7,10,15,18,21} To the authors' knowledge, this is the first study to investigate OCA in Botswana, where epidemiologic data are lacking and local support programs for PWA are limited. By exploring the concerns with physical, psychosocial, and environmental health facing PWA throughout life, we aim to provide a baseline of information on the factors affecting QOL of PWA in Botswana, to illuminate strategies that can be undertaken to improve overall QOL in this population.

METHODS

We conducted qualitative semistructured interviews of PWA in Botswana. Participants were selected by convenience sampling from a larger cohort of 50 PWA older than 18 years old who were recruited from dermatology and eye clinics at Princess Marina Hospital or Tshimologo Albinism Association meetings in Gaborone, Botswana.

After informed consent, trained research assistants conducted interviews in participants' language of preference (Setswana or English) in a private room. A semistructured interview guide was used to explore issues of concern with life

experiences across physical and mental health, education, employment, social interactions, and stigma/discrimination. Pertinent topics were decided based on literature review and author VLW's experiences working with OCA patients. Two pilot interviews (not analyzed in the results) were conducted to focus the interview guide. Additional interviews were conducted until saturation of themes was achieved. Interviews were recorded with consent and transcribed verbatim by research assistants.

QOL is complex and difficult to define, thus we chose to use a single framework outlined by the WHO for organizational structure.¹⁷ The WHO breaks down QOL analysis into domains: physical, psychological, social interactions, and environmental health.²² We combined social and psychological into one category because of the overlapping nature of topics covered.

Data were analyzed using the principles of thematic analysis.²³ Interview transcripts were uploaded onto MaxQDA software.²⁴ VLW read and reread the transcribed interviews and inductively developed codes from the data. EEA independently reviewed the data and developed codes. After rereading, both researchers agreed on final codes. Using the code family function, similar codes were grouped into categories based on identified relationships. VLW and EEA further interrogated the descriptive categories in the theoretic context of the WHO QOL domains and then agreed on overall categories to describe the data codes. Further interpretation and analysis of the categories led to the development of subcategories with themes to further describe the data that emerged from interview codes.

The study was approved by the institutional review boards of the University of Pennsylvania, University of Botswana, Princess Marina Hospital, and Ministry of Health and Wellness of Botswana.

RESULTS

Demographic Factors

Twenty-seven participants were interviewed with a male/female ratio of 1:1.6. The mean age was 37.9 (standard deviation, 14.7) with a range of 21 to 75 years old. All participants identified their ethnicity as Batswana.

Physical Health Factors

Skin health concerns

Every participant emphasized skin health as one of their greatest priorities in life, and many indicated a good understanding of the effects OCA had on their health: *"My skin easily gets burnt by the sun. If I do not protect myself I can get sores."*

(Participant [pt] 26). There was an understanding that engaging in sun protection was important to prevent the development of skin cancer: “[Sun protection] is important because it prevents me from being killed by skin cancer.” (pt 36). Even more importantly, many participants understood the benefits of preventative measures in maintaining their health: “It’s very important to avoid sunburn. It is better to prevent than cure.” (pt 14).

Despite knowing the importance of sun protection, the degree to which participants understood how or were able to successfully protect themselves from the sun varied. Common methods for sun protection included clothing, shade structures, or staying indoors. However, a majority expressed difficulty in obtaining protective clothing because of finances or lack of availability in shops. Many felt helpless to avoid the sun because their activities of daily life, especially accessing transport and employment duties, required them to be outside: “...I honestly think there is nothing I can do to improve sun-protection practices because I can’t change the type of work I do, and I got other stuff to do for my life.” (pt 6). The lack of indoor employment opportunities created an internal struggle to balance their health needs with the need to earn money to support themselves: “My jobs often require me to work outside, and I have no choice but to do it because I have to find some way to make money.” (pt 5).

Second to sun avoidance, sunscreen was described as the most important tool for sun protection and a central focus of participants’ lives: “I cannot live without sunscreen.” (pt 32).

“[Sunscreen] is a medication for us. It is life-saving, and we need it just like people need their blood pressure medications.” (pt 8). However, nearly all participants faced challenges in obtaining an adequate supply of sunscreen including limited availability in pharmacies/shops, inability to reach places where it was available, inability to afford purchase, or dislike for the available sunscreen options.

Eye health concerns

One of the most common visual impairments associated with OCA is poor visual acuity and/or low vision, which can be significantly improved or corrected with appropriate treatment.^{1,8,25,26} Participants universally indicated challenges in accessing refractive eye examinations and/or subsequently obtaining prescription eyeglasses. Although eye care and eyeglasses are covered through the public health care system in Botswana, rarely were participants able to obtain them. Health care system barriers included few

clinicians performing refractive examinations, one location with the equipment to make refractive lenses, and lack of supplies and/or technicians to produce eyeglasses. Nearly all participants lacked the finances to purchase eyeglasses or vision aids, and as a result, most had lived with some level of impaired vision.

Visual dysfunction had far-reaching consequences throughout participants’ lives. Nearly all emphasized the direct effect visual impairment had on their education, indicating various barriers to successful learning summarized in **Table 1**. Participants lamented that low vision was the direct cause of their poor performance in school: “If I had good vision I would not have failed like I did at school.” (pt 9). Additionally, low vision vastly narrowed employment opportunities, which were already limited by lack of education: “Vision challenges really affect me because some jobs require a person with good vision, so I have no chance at these. Because of my poor vision I stay at home. I can’t find work.” (pt 29). Navigating what would commonly be considered simple activities of daily life were fraught with challenges: “getting around is a huge struggle. People don’t realize how much of our society is set up against people with visual impairment. Why does there have to be glass doors? Why does there have to be shiny metallic windows or glass that reflects in all directions making it impossible for me to see without pain?” (pt 7). Low vision often precluded participants from engaging in social activities, such as dancing, sports, or games that “require one to have normal vision and play at a particular pace which I couldn’t keep up because of my vision.” (pt 6).

The positive impact of successfully obtaining treatment to correct visual impairments was significant, resulting in some participants feeling their visual challenges were completely solved: “I had problems with my vision when I did not have spectacles. When I had them, it was okay.” (pt 28).

Health care access challenges

Health care access is a complex and multidimensional topic that has been described to rely on the interconnected components of availability, accessibility, affordability, adequacy, and acceptability.²⁷ Although Botswana offers universal coverage to its citizens,²⁸ a unifying theme was that, despite attempts, participants faced difficulty in successful acquisition of health care. Barriers faced because of various health care access components are detailed in **Table 2**. One patient poignantly summarized her difficulty navigating

Table 1
Factors contributing to educational environments of people living with albinism in Botswana

Categories	Specific Factors	Representative Quotations (Participant Number)
Health-related barriers to learning	<p>Vision- related Challenges</p> <ul style="list-style-type: none"> • Difficulty seeing the board • Difficulty writing on the board • Difficulty reading (font size, color of fonts/background) • Difficulty using computers • Lack of materials for self-study • Time required to transcribe notes impeded time to learn • Not allowed extra time to complete assignments/tests • Distracting eye pain (from straining, photophobia) • Unable to access eyeglasses to correct low vision <p>Skin- related Challenges</p> <ul style="list-style-type: none"> • Distracting skin pain (from sunburns) 	<ul style="list-style-type: none"> • "I wouldn't see well, but if I come closer to the board, I was told that I distracted the other students...even though I understood Maths, I won't be able to see how the Math problems are solved to learn more and do well in the subject." (pt 35) • "...it was hard to write tests on the board with poor vision." (pt 10) • "...reading small black letters on a white page was very difficult." (pt 26) • "I didn't continue with my studies because at tertiary...the types of computers were just not big enough for me to see and they would just tire my eyes." (pt 32) • "I had to wait for others to finish and borrow their books to write [notes]...sometimes they would refuse" (pt 10) • "It made me to be behind with my school work because instead of revising I would be writing notes making me grasp little." (pt 10) • "It was just hell. I was submitting my assignments late, I was finishing my tests late.... Teachers did not allow this so I was always in trouble." (pt 7) • "...when things were written on the board. I had bad eyesight...it would be painful." (pt 37) • "...there would be too much light into my eyes...and that would be painful." (pt 37) • "My parents knew I was short sighted but we were [too] poor for them to buy me spectacles." (pt 45) • "For sure if the sun has really hit me, I cannot be able to go to school or to work." (pt 7)
	Emotional barriers to learning	<ul style="list-style-type: none"> • Lack of confidence in their own intelligence • Shame for not understanding their own educational needs • Emotional distress from stigma-based bullying

(continued on next page)

Table 1
(continued)

Categories	Specific Factors	Representative Quotations (Participant Number)
Discriminatory barriers to learning	<ul style="list-style-type: none"> Given lower priority in classrooms Teachers fear PWA Teachers lack knowledge on needs of PWA Teachers ignore bullying of other students Teachers shaming/punishing for special needs Educational opportunities are held back 	<ul style="list-style-type: none"> "Teachers did not give us the same opportunity as other kids. Even when we were better than them, they always got first priority. I think because they didn't want to deal with us and our poor vision..." (pt 33) "Some of the teachers were still afraid of us with albinism and so they were not making adjustments." (pt 13) "The teachers often have no knowledge about albinism or how to talk to the children, how to treat them, what they need, what visual problems they have..." (pt 32) "Some kids did not treat us well... I don't think teachers paid attention... I also did report to teachers, but they did nothing." (pt 45) "...they would be spitting at me...it affected my ability to learn and to listen in class. Even if I would try to tell the teacher, she would be just ignoring this." (pt 21) "...even if I would ask the teacher to move forward they would say, 'No, no, no!' and they would scream at you and make you not have interest in going to school." (pt 32) "Every time [I used the special needs bus transport], I would be like 20 or 40 min late and they [my teachers] would try to beat me [for being late to my class]." (pt 7) "My parents did not want to take me to school because they believed I would not see written letters...Right now my age mates have achieved so much more in their life because of their education." (pt 14)
Resource limitations to learning environment	<ul style="list-style-type: none"> Overcrowded classrooms Teachers not trained for special needs of PWA Limited or no access to special education programs 	<ul style="list-style-type: none"> "There were too many [students] in class and the teacher was not able to give me the attention and help I needed." (pt 31) "Some teachers were not trained to assist all students according to their need." (pt 10) "There was no special education, I was taught just like any other child who doesn't have albinism." (pt 5) "I was going to a public primary school in Lo-batse and they actually had a special needs department but I was not part of that. I tried to ask to be a part of that program, but they refused. They didn't see me as different from other people." (pt 7)

(continued on next page)

Table 1
(continued)

Categories	Specific Factors	Representative Quotations (Participant Number)
Positive changes to learning environment	<ul style="list-style-type: none"> • Teachers adjust learning environments • Special education programs • Support from peers • Support from parents 	<ul style="list-style-type: none"> • "The teachers that did know would write on the board very large and in a dark color so that I could see. They would ask me where is it that I would be most comfortable, and I would tell them the front of the class and then that is, where I would sit." (pt 13) • "When I was about to hit rock bottom...I found out there was a whole center dedicated to helping people like me with visual impairment. They taught me how to use visual tools, zoom text and JAWS. This made a huge difference in my education and allowed me to finish my studies successfully. But I can't help but wondering where was this unit for the first 2 y of my studies?" (pt 7) • "At tertiary level I enjoyed my school days since my colleagues would not let me be alone. They would call me if I try to isolate myself and make me feel like I should be a part of the group." (pt 23) • "My parents supported me and always informed my teachers to help me see better throughout my school days." (pt 23)

the public health care system in Botswana for treatment of a lip sore. Her care was delayed more than a year, resulting in the growth of a large nonoperable SCC of the lip (**Fig. 1**):

"They [the healthcare system] delayed to help me...but I used to come here [the hospital] daily...I first came when it [the skin cancer] was smaller...they kept doing tests and the results kept pending...and it grew bigger... I started at [my local clinic] who said should go to Oncology, and Oncology said I should go to Dental...then Dental said I should go back to Oncology to check if it is cancer. Because they wanted to do operation and the other doctors said you can't do operation without knowing the nature of the lesion, so go back to Oncology to do tests...It grew to this [size] before I was able to come to dermatology." (pt 9).

Psychosocial Health Factors

Stigma and discrimination

Participants reported a consistent onslaught of stigma and discrimination throughout life because of their outwardly identifiable genetic disease, resulting in a substantial negative impact on social interactions, employment, education, and

psychological health (**Table 3**). Albinism-associated stigma was experienced as feeling rejected, feared, isolated, "not human," "invisible," "diseased," or that they "do not exist." Discrimination was experienced as being made to feel of lesser value to others; socially excluded; and restricted in activities of daily living, education, and/or employment: "...other people [make me] feel like I am nothing and I have no value." (pt 5). Many expressed an overall sense that society was "avoiding trying to help us with albinism." (pt 29). Albinism-associated stigma was believed to even surpass the stigma of human immunodeficiency virus (HIV), which has been well-demonstrated as a major issue in Botswana society.²⁹⁻³¹

Social interaction challenges

Stigma and discrimination created a clear impediment to the development of interpersonal connections associated with positive features of trust, respect, and esteem. From early childhood, some participants felt stigmatized and discriminated by their own families. Building and maintaining relationships with peers and romantic partners was strained. Interactions with members of society were fraught with unpredictable forms of harassment, marginalization, and restrictions. Even those who thought they found love and trust

Table 2
Health care access challenges for people living with albinism in Botswana

**Health Care
Access
Challenge
Categories**

Challenges Faced

Representative Quotations (Participant Number)

<p>Availability: Do providers have the resources needed for diagnosis and management?</p>	<p>Limited availability of:</p> <ul style="list-style-type: none"> • Medications through government pharmacies • Equipment needed to treat the skin and eyes • Diagnostic tests leading to slow turnaround time • Specialist physicians in Botswana 	<ul style="list-style-type: none"> • "Things like sunscreen, tablets... sometimes the hospital just doesn't have what I need." (pt 21) • "...today I came for cryotherapy but it was not there. So even when I can get to the clinic, it doesn't mean that I will be helped or that my problems will be fixed." (pt 45)
<p>Accessibility: Do patients struggle because of distance or time required to receive needed care?</p>	<p>Patients struggle with:</p> <ul style="list-style-type: none"> • Navigating the multiple steps needed to get treatment • Specialist appointments that are: <ul style="list-style-type: none"> • Difficult to obtain • Have long wait times • Require long distance travel 	<ul style="list-style-type: none"> • "It took long for them [the health care system] to help me, but I used to come here [the hospital] daily..." (pt 9) • "I live very far out...maybe 10-15 h so I need support to get transport to Gabs to see a dermatologist because there is no one in my area that can do skin checks..." (pt 13) • "I think everywhere in our country ...we struggle with waiting times...one time I had to live with a tumor for close to 6 mo before it could be operated on..." (pt 7)
<p>Affordability: Do patients struggle to pay for needed health care or health care-related items?</p>	<p>Patients are unable to afford:</p> <ul style="list-style-type: none"> • Purchasing medications (when not available through public health care system) • Sunscreen • Time off work for clinic visits • Transport to clinics/hospitals 	<ul style="list-style-type: none"> • "...I live 50 km away from Gaborone, it costs me more than I have to get to Gabs to see the dermatologist." (pt 26) • "Although I know the health care is available it doesn't always mean that it is easy to access. I find it difficult to ask for time off from work as often as I need." (pt 7)
<p>Adequacy: Do patients feel satisfied with the health care provided?</p>	<p>Patients believe care is inadequate because they:</p> <ul style="list-style-type: none"> • Believe it is ineffective or futile • Prefer traditional medicine or religious cures • Are unhappy with treatment side effects • Family/friends do not agree with the treatments 	<ul style="list-style-type: none"> • "...you start thinking to yourself 'ah i don't think the hospital helps. I don't need to go there'. [PWA] end up just giving up and maybe never going back. Or maybe they try other cures like from their church or family." (pt 7) • "For those in remote areas it can be the family members keeping persons with albinism from seeking help and getting to see their doctors." (pt 8) • "... I dread having to face getting my skin cut or sprayed [at the dermatologist]...people around you will try to talk you out of going to the doctor." (pt 7)

(continued on next page)

Table 2
(continued)

Health Care Access Challenge Categories

Acceptability:
Do patients trust providers and believe that care is in line with their cultural and social values?

Challenges Faced

- Patients believe care is unacceptable because they:**
- Experience stigma/discrimination from providers
 - Experience societal stigma/discrimination for needing medical care
 - Feel neglected by the health care system
 - Feel scared to have leave their village for health care

Representative Quotations (Participant Number)

- "Most of the time nurses just brush us off when we present with sores to the local clinic. They make it seem normal and just give us calamine lotion and then we just get worse." (pt 33)
- "You get labeled as 'always out sick'...that alone makes you not have the confidence to go to the hospital. So you end up missing the most important thing that can make a difference in your life..." (pt 7)
- "An albino needs sunblock and spectacles just like an HIV positive person needs ARVs...because she [the health care system] does not take statistics of albinos [like is done for HIV], she is unable to provide them adequate health care." (pt 35)
- "[PWA] might be scared to leave their own area...so in this way they are kept from getting proper health care." (pt 13)

in marriage could still face stigma from their partner: "Albinism became an issue that broke apart my family... Out of nowhere [my husband] developed this problem with albinism and not only turned against me but turned my children against me. He said 'just know that all along I was just making you a favor. People like you don't get married'..." (pt 32). Social stigma was strong enough to affect parents of PWA, evidenced by alarming reports of young mothers committing suicide after birthing a child with OCA (pt 8, 32). Practices of self-harm, abandonment, and even

infanticide have similarly been described in families of PWA in other African countries.³²

Psychological impact

A cascade of negative psychological consequences developed from these experiences of stigma and discrimination (Table 3). Recurrent social rejection and lack of positive interpersonal experiences led to feelings of sadness, hopelessness, helplessness, resentment, fear, and shame typified by such sentiments as: "I despise myself" (pt 1) and "what have I done to deserve this" (pt 3). Negative thought and behavior patterns including low self-esteem, low self-efficacy, self-isolation, distrust, help-avoidance, and self-harm were common results. Some developed a habit of self-perpetuated negative thoughts that spiraled into a vicious cycle of learned helplessness, preventing participants from having enough self-efficacy to engage in measures to improve their life circumstances: "As people with albinism, we internalize the hate others have for us and treat ourselves as worthless. How can we help ourselves when we don't see our lives worth living? When we don't think ourselves worthy of love and respect from others. In turn this makes us angry and resentful to others and this builds a viscous cycle of pushing people away and becoming more and more isolated." (pt 7).



Fig. 1. Large invasive squamous cell carcinoma tumor of the left lower lip that grew during the course of diagnosis and treatment delays in a patient with albinism in Botswana.

Table 3
Psychosocial impact of stigma and discrimination on people living with albinism in Botswana

Categories and Specific Challenges	Representative Quotations (Participant Number)
Social Interaction Challenges	
<i>With Family</i>	
<ul style="list-style-type: none"> • Not feeling accepted or supported by family • Restricted from family activities/events 	<ul style="list-style-type: none"> • "... I would worry when discriminated by people at home where would I go and what would I do then..."²³ • "... within my husband's own family, even his sisters told me that we don't love you."⁸
<i>With Peers</i>	
<ul style="list-style-type: none"> • Difficulty initiating and maintaining friendships • Exclusion from peer activities • Bullying from peers 	<ul style="list-style-type: none"> • "Someone may have the desire to be my friend but then their family they don't accept me, and they force them to reject me."²³ • "...I will be given a separate dish from others...my friends would tell me 'I can't eat with this one' or 'I can't sleep with this one' or 'I can't bath with this one' ...in many ways I would be singled out."³⁵
<i>With Romantic Relationships</i>	
<ul style="list-style-type: none"> • Difficulty initiating and maintaining relationships • Emotional bullying from significant others 	<ul style="list-style-type: none"> • "It [albinism] is the reason why the father of my child is gone, because his friends will tell him 'how could he be with someone like this, why didn't you find a better person than this person with albinism.'"²⁹ • "Then he [my husband] came to me and said ... 'just know that all along I was just making you a favor. People like you don't get married. I did you a favor to marry you.'"³²
<i>With Society</i>	
<ul style="list-style-type: none"> • Strangers avoid contact • Strangers react with fear and/or disgust • Verbal and/or physical aggression from strangers • Restricted from communal activities/events • Objectified as inhuman • Ignored when seeking help from societal/government institutions • Facing greater stigma than people living with HIV • Mothers of PWA react by inflicting self-harm • Stigmatized due to visible signs of medical treatment 	<ul style="list-style-type: none"> • "When you try to greet someone, they act like they don't see you, like you do not exist."²⁹ • "I experience [stigma] from the society... They despise and look down on us. Some act like we smell and sometimes spit saliva."⁴⁵ • "When there are community works... I cannot participate... people do not want me to touch the food they eat."²³ • "...we were told that we were not people, albinos are not human beings so we can't report mistreatment [at police stations]."⁸ • "In government offices...they will say that they will be right back but then they never come back. It is clear that they are avoiding trying to help us with albinism."²⁹ • "Being an albino is most discriminated than having HIV since some people are afraid of us, some feeling disgusted by our condition and we cannot hide it like you can with HIV...."²⁰ • "This past month there was a mom who committed suicide because she had a baby with albinism. You don't hear about that with HIV."⁸
Employment Challenges	
<ul style="list-style-type: none"> • Excluded from opportunities to apply/interview • Denied employment offers 	<ul style="list-style-type: none"> • "I was discriminated because of my skin color in jobs I have applied for...Eventually I only got

(continued on next page)

Table 3
(continued)

Categories and Specific Challenges	Representative Quotations (Participant Number)
<ul style="list-style-type: none"> • Fired without cause • Excluded from promotions • Bullied by coworkers/colleagues • Stigmatized for needing time off for health-care needs 	<p>a job because there was no one else [applying].”³⁰</p> <ul style="list-style-type: none"> • “Even colleagues that I have been working with for years, I hear them whisper about me. Saying I don’t deserve the position I have.”⁸ • “I find it difficult to ask for time off from work... I feel like others notice and keep track. It makes me feel diseased and like people feel that I am not as human because I need to see doctors so much.”⁷ • “They stigmatize me by not letting me progress...They cannot give me a reason for why I do not get allowed to go for further training, they just give a reject to my requests.”⁸
Educational Challenges	
<ul style="list-style-type: none"> • See Table 1 	
Psychological Impact Challenges	
<p>Major Emotions:</p> <ul style="list-style-type: none"> • Sadness • Hopelessness • Helplessness • Resentment • Fear • Shame <p>Resulting thought/behavioral patterns:</p> <ul style="list-style-type: none"> • Low self-esteem • Low self-efficacy • Self-isolation • Distrust of others • Help avoidance and denial • Self-harm/self-reproach • Self-perpetuated negative thought pattern 	<ul style="list-style-type: none"> • “Yes stigma affects, it makes me feel sad and ask myself what wrong have I done to deserve this.”³ • “I am sometimes hopeless...sometimes I wonder if I will manage. For example, when people are registering to receive government programs of poverty alleviation whereby we get goats. I do need them but I would wonder if I will manage them properly so in the end I don’t end up even applying.”³⁶ • “I feel trapped like I cannot go where I want. Imagine you are not feeling well and you have no way to get to a doctor...You could even go to the bus stop and not know what routes to take. You feel isolated inside yourself because you are not exposing yourself to people and are hiding most of the time.”³² • “So many people cocoon themselves because maybe they have been denied or failed so many times in the past and now they just give up. They don’t even seek the resources or help that is, available.”⁶ • “I even broke a bottle and stabbed myself to hurt myself because there was too much pain. I thought, ‘If I wasn’t like this with this skin...’”³² • “People with albinism just choose to suffer instead of standing up for themselves.”⁸ • “We want things to change but...if people try to talk to us to bring change we are not so sure if it is real, you don’t trust them and pressure keeps building and depression keeps building.”⁷

Myths and superstitions

Pervasive myths and superstitions associated with albinism emerged as additional negative contributors to psychosocial health. These included misinformation about how albinism is contracted and various beliefs about supernatural powers of PWA (Table 4). Participants reflected that these erroneous beliefs were likely fueling society's stigma/discrimination toward PWA. These beliefs also negatively contributed to the information participants had available to build their own self-concept. Particularly for children just learning about themselves, myths/superstitions seemed to impair their ability to develop a positive self-image and a sense of trust in others: *"It affected me because I didn't have any education about those myths. I didn't know if they were true or*

not when I was a child.... nobody was touching me or maybe one would run up to me and touch me just fast to see if the color could change. It made me very hurt. It made me feel that I was not a person. It was very tough." (pt 21).

Environmental Health Factors

Participants discussed several factors affecting QOL in their external sociocultural environment, including issues with personal development, financial security, safety, and human rights.

Educational barriers to personal development

In addition to the vision-related barriers previously discussed, emotional barriers, discriminatory barriers, and resource limitations further compounded learning challenges for PWA (Table 1). Bullying

Table 4
Myths and superstitions about albinism in Botswana

Myths/ Superstition Categories	Specific Examples	Representative Quotes (Participant Number)
Myths about the humanity of PWA	<ul style="list-style-type: none"> • PWA are not human • PWA do not die • Men cannot truly love a woman with albinism 	<ul style="list-style-type: none"> • "I hear people with albinism do not die but disappear." (pt 14) • "I hear them say all the albinos disappear and I felt insecure to hear that I disappear." (pt 35) • "When a man comes to a women with albinism he doesn't love her but he just wants to compare with a normal person or he is doing her a favor." (pt 8)
Myths about the contagion of albinism	<ul style="list-style-type: none"> • You must spit on yourself after seeing a PWA to prevent contraction of albinism • You will contract albinism by stepping where a PWA has been • Pregnant women who touch a PWA will give birth to a child with albinism 	<ul style="list-style-type: none"> • "You have to spit on yourself when you see one to avoid becoming one." (pt 7) • "They say if you happened to stepped where an albino has stepped you're also going to change and you will have an albino child." (pt 21) • "The rumors I hear is that when you sit next to an albino and you are pregnant, you will give birth to a child like an albino." (pt 29)
Good luck superstitions	<ul style="list-style-type: none"> • Body parts of PWA can bring good fortune • Body parts of PWA cure diseases in African traditional medicine • PWA cannot contract HIV • Having sex with a PWA can cure HIV 	<ul style="list-style-type: none"> • "People with albinism are harvested for 'muti' for traditional medicine and to bring good luck." (pt 20) • "I have heard of people using body parts of people with albinism for traditional medicine." (pt 26)
Bad luck superstitions	<ul style="list-style-type: none"> • The touch of a PWA brings bad luck • Families of PWA are cursed 	<ul style="list-style-type: none"> • "People did not want me touching their food because they thought I was bad luck." (pt 7) • "Some would say our family is cursed to have a child like me." (pt 21)

Abbreviation: HIV, human immunodeficiency virus.

from peers was common, and teachers would ignore or even shame students trying to exert their needs. Participants overwhelmingly complained that their educational environments did not provide them with an equal opportunity to “learn properly.” As a result, they often avoided school, performed poorly, or quit at a young age.

Even when special education resources were available, they were not readily accessible: *“I found out there was a whole center dedicated to helping people like me with visual impairment.... I think about how long I suffered needlessly when they had everything I needed but were unwilling to share it.”* (pt 7). For those who could access educational support, the impact was immense. One participant was able to excel in a challenging tertiary educational program as a result of an adjusted learning environment provided by an expatriate teacher: *“That was the very first time that any teacher took notice of my impairment and tried to help. I was able to finish the program and pass because of his help. The other lecturers didn’t think that I should be treated differently than the other students and in our country there is no laws that mandates anything for visual disabilities.”* (pt 21).

Employment barriers to personal development

Participants expressed frequent frustration with an inability to develop meaningful careers. Many were only able to get jobs in menial labor or within the government’s public works program that required them to work long hours outside being exposed to dangerous ultraviolet radiation.³³ Visual impairments and educational deficits surfaced as root causes precluding satisfying employment and a consequent improvement in life circumstances: *“My vision problems affected me in that I could be educated, have a job to live better if I was able to see enough to get through school.”* (pt 1).

Successful employment was also hindered by stigma and discrimination (see **Table 3**). Employment options suitable for the low vision and sun sensitivity of PWA were lacking, and employers were unwilling to make allowances for special needs: *“when employers see that I cannot be outside, they do not even give me a chance at a job.”* (pt 17).

For the few successfully employed participants, stigma and discrimination impeded enjoyment of work and limited opportunities for promotion within their fields: *“At work, some people do not like me. Some feel disgusted. Some would not even want to talk to me or sit next to me, all because of the color of my skin. It makes it hard to enjoy work or do my job well.”* (pt 26).

Financial security concerns

Additional consequences of poor education and limited employment opportunities were lower socioeconomic status and poverty. Many were struggling to access basic needs, such as food, shelter, transportation, health care, and education for themselves and their families. Low income prevented purchase of adequate clothing and personal care products that could help maintain skin health and comfort. Inability to access welfare support was a common concern: *“My doctor once wrote me a letter to give to social worker so that I get monthly rations, but even to now I am unable to get this support. So I am left with only the P200 that my child gives me...”* (pt 45).

Safety concerns

A general sense of anxiety and fear permeated the lives of many participants, namely because of reports of ritual killings of PWA across Africa and concern that these attacks could also occur in Botswana. Participants felt *“always afraid”* (pt 1) to be alone, to travel freely, or go out at night: *“I feel unsafe thinking that, at any time, someone might want to kill me and use my body parts.”* (pt 26). Others felt unsafe because of the stigma/discrimination directed at them and concerned that verbal abuse might turn into physical abuse. Some experienced minor physical aggression, threats of violence, persecution, and/or attempts at kidnapping, but our participants gave no reports of ritual murders.

Additionally, low vision made participants feel inherently unsafe in their environments. Many struggled to navigate daily activities: *“In the street ...we don’t feel safe to cross the road.”* (pt 23). Without being able to clearly see their surroundings, participants felt at high risk for accidents and criminal violence: *“I was once attacked at night by thieves. I couldn’t see them until they were right on top of me... It’s dangerous.”* (pt 32).

Disability rights issues

Botswana’s government upholds the goals of improving social welfare and empowering disadvantaged groups through various welfare services and poverty eradication programs.³⁴ However, many participants reported an inability to access these services because of stigma/discrimination, difficulty navigating the process of application, or directly being denied: *“...it is not as easy as people who are old, in wheelchairs or pregnant because for us we get people saying “no you guys are lying you are just like us why would we give you preferential treatment....”* (pt 7).

At the time of this publication, Botswana has no specific disability rights in place and does not officially recognize PWA as disabled by law. As a result, participants often had difficulty deciding whether they considered themselves disabled and, thus, to which rights and protections they were entitled. Many believed albinism should be considered a disability to give special protections that could decrease the challenges faced throughout life: “[Our biggest problem is] not being viewed as disabled and being forced to compete with the rest of society in day-to-day life. There are no protections in place to help us and we are no match for the world the way it is set up.” (pt 7).

However, there was significant trepidation around the word “disability” and concern that labeling themselves as disabled might, in some ways, lessen their already low status in society. To avoid stigma/discrimination, some participants expressed a desire to be seen and treated as normal: “We are not having a disability. We are just like anyone else and we can do things like everyone else. This would help people to accept those with albinism as they are.” (pt 13). For some, there was a lack of understanding that disability rights legislations aim to increase equitable access to basic human rights and social inclusion to pave the way for less societal stigma/discrimination.

DISCUSSION

Our qualitative investigation of the life experiences of PWA in Botswana revealed that numerous intersecting physical, psychosocial, and environmental factors can contribute to lower QOL in this population (Fig. 2). These findings are consistent with the negative psychosocial impact of OCA reported in other African and South American countries.^{5,7,10,15,18,21,35} There was significant overlap and interplay between QOL factors, indicating that negative influences and challenges can become compounded and multiply throughout life. An overlying theme connecting the issues faced by PWA was difficulty obtaining equitable rights and access within Botswana society.

Although health care access is a common problem across Africa,³⁶ Botswana positively stands out as a country that offers universal health care for citizens.²⁸ However, participants reported significant health challenges, indicating the need to improve practical access for PWA. Upscaling dermatology, oncology, and ophthalmology skills, currently only available at limited district/tertiary hospital levels, is critically needed for PWA. Sensitizing providers across Botswana to the special

needs of OCA and giving PWA priority status as a vulnerable population within the health care system would allow more rapid and reliable access to needed care.

Participants primarily suffered skin and eye challenges, as has been reported in previous epidemiologic studies.^{1,2,4,6-9} An understanding of their own health risks was not enough to prevent sun damage and skin cancers, because most faced barriers obtaining sunscreen/sun protective clothing and could not avoid daily sun exposure. Interventions to widely distribute sunscreen that is consistently available for free or a low cost are vital to give PWA a mechanism to protect themselves regardless of their required work/life activities. Sunscreen is included on Botswana's public medication formulary; however, limited supplies are available for the entire population. One of the authors (VLW) initiated a program to improve health care for PWA at Princes Marina Hospital through prioritized patient scheduling, obtaining equipment for skin cancer treatment, creating patient and provider education materials, organizing awareness events, and most importantly distributing free sunscreen with the support of Lady Khama Charitable Trust. However, this program only reaches patients who can access regular dermatology clinic visits. Outreach campaigns offering clinical care to underserved areas along with the distribution of durable shade devices and/or reusable ultraviolet protective clothing could augment skin cancer prevention in a cost-effective and sustainable way.³

Vision-related challenges were the most frequently emphasized issue, which had a negative impact across all three domains of QOL. Prior research in African OCA populations has indicated visual impairments are nearly completely correctable with prescription lenses or low-vision aids.¹ However, in Botswana, few participants were able to obtain the necessary health care services to achieve functional vision. Similarly, in neighboring South Africa, one study demonstrated that 85% of children with albinism were living with less than 30% use of normal vision.⁹ Living with low vision from childhood to adulthood had far-reaching effects on education, employment, financial security, health care access, social interactions, safety, and the psychological well-being of participants. Visual disabilities effectively limited the opportunity of PWA to become active participants in society. The cost of extending low-vision support services and prescription eyeglasses to PWA is a small price compared with the benefits to be gained from lifting this population out of a lifetime of disability. Standing Voice, a well-established albinism support organization, has

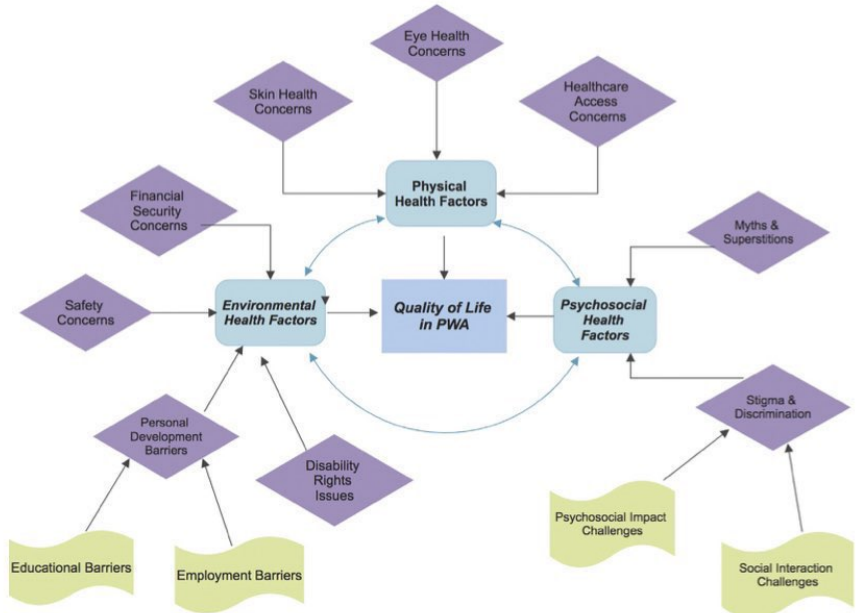


Fig. 2. This figure demonstrates how physical, psychosocial, and environmental factors can intersect and compound to contribute to lower QOL for PWA in Botswana.

developed a highly successful integrated skin cancer prevention and vision program in East Africa through partnerships with local governments and health care systems. Through large scale, rotating outreach clinics, they provide low-cost, on-site skin and eye care to hundreds of patients, dispensing up to 176 pairs of eyeglasses at a single outreach visit.³⁷ Their programs demonstrate the feasibility of high impact, scalable, and sustainable interventions for OCA health.

Psychosocial health is a cornerstone of QOL that is overlooked in developing countries facing more dire health crises, such as the HIV epidemic in Botswana.^{38–40} However, without concurrently addressing psychosocial needs, interventions to increase the physical and environmental health of vulnerable populations may be less effective. Stigma and discrimination seemed to permeate all aspects of our participants' home/school/work and social lives. These effects have been similarly emphasized in other OCA studies.^{2,5,7,9,15,16} Major psychological consequences included denial, self-reproach, and help avoidance behaviors, which could hinder efforts to support this population. Without the ability to feel safe, meet basic needs,

and feel supported/included within society, our participants neither felt worthy of accepting support, nor had the capacity to benefit society by reaching their true potential.

Environmental health factors of personal development, financial security, safety, and disability rights were also heavily influenced by stigma/discrimination and society's lack of awareness of the special needs of PWA. The educational system can provide early support for children to develop the skills needed to lead a productive and satisfying life.^{5,7,41,42} Negative experiences commonly triggered PWA to discontinue school, and poor education is a known risk factor for several negative health and QOL factors.^{41,43,44} There is untapped potential for interventions to improve educational outcomes for PWA in Botswana and other African countries. Widespread teacher education programs that emphasize identifying and adjusting to the needs of OCA students have been successful in Tanzania.⁴² PWA can suffer lifelong consequences when they are not guaranteed the right to access education suitable for their special needs. Similarly, equal employment protections

are needed to prevent the unfair challenges PWA face in obtaining safe and meaningful employment, a common struggle noted in surveys of PWA in other African countries.^{16,18}

A repeated theme that summarized the intersecting factors contributing to low QOL was the viscous cycle that can trap PWA. It starts in childhood with visual dysfunction, leading to poor education combined with negative psychosocial interactions fueled by stigma and discrimination. Rare positive external influences trigger the development of a negative self-concept. Later in life, limited job opportunities caused by poor education and the physical limitations of OCA lead to higher rates of poverty. When jobs are obtained, the chance for upward mobility and success is thwarted by stigma/discrimination. Financial insecurity makes obtaining and maintaining health care more difficult. Because outside information is conflicting, PWA develop a sense of denial about their condition. There is confusion about whether they should fight for disability rights or fight to be “normal” citizens. Governmental support in the form of health care, social welfare, and disability services are available but, realistically, unattainable, suggesting efforts need to be made to assist PWA in understanding available programs and obtaining equitable access. Each time a participant’s attempt at obtaining help was defeated, it encouraged a sense of helplessness and mistrust of society and its institutions. A dangerous sense of learned helplessness seemed to develop over time, encouraging PWA to effectively withdraw by not engaging in their own health care, personal relationships, or activities within their environments. Early positive and supportive influences in the lives of PWA would be key to prevent this negative path to low QOL. Models of successful OCA programs in other countries have used existing networks of OCA support groups as a means of disseminating education and linking individuals with support services to improve finances, education, health care, employment, and safety.^{37,45} Because safety and trust was an expressed challenge in our cohort, we suggest interventions for PWA be implemented through groups with which they already feel a sense of connection and trust, such as OCA support groups, disability support groups, or religious groups.

In conclusion, our OCA cohort in Botswana faced similar challenges to PWA in other regions: a pervasive difficulty in obtaining equal rights to physical, psychosocial, and environmental health, which contributed to lower QOL.^{2,3,7,10,35} Based on recommendations in the United Nation’s Universal Declaration of Human Rights⁴⁶ and examples set by other African countries making strides in OCA rights, improving the lives of PWA in

Botswana should start with ratifying disability rights protections and formally including OCA as a qualification for disability.^{47,48} Currently, Botswana is 1 of only 11 countries on the African continent that have not ratified the United Nation’s Convention on the Rights of Persons with Disabilities.⁴⁹ Significant efforts are needed to increase awareness and education on OCA across society, and institutions need legal support to help guide change. PWA need disability rights protections to guarantee access to skin and visual health, equal opportunity for personal development, access to governmental support programs, and social inclusion. The QOL framework we outlined could be used as a model to help explore the challenges and potential solutions for PWA in other regions globally.

Study limitations include the difficulty in generalizing results based on our convenience sample of participants engaged in positive societal activities (support groups or health care) in the capital city. Our results may differ compared with more isolated, rural communities in Botswana. Future studies should aim to investigate the prevalence, incidence, distribution, demographic features, and health outcomes of PWA, and triangulate our findings with quantitative QOL measures to improve understanding of this population.

CLINIC CARE POINTS

- Clinicians should be aware that visible skin diseases like oculocutaneous albinism can affect quality of life in a variety of ways that are dependent on local factors such as disability rights and cultural beliefs.
- To maintain skin health, clinicians should ensure patients with oculocutaneous albinism understand the risks of skin cancer and have access to sunscreen, sun protective clothing, and regular skin exams by a dermatologist.
- To prevent disabling visual dysfunction, patients with oculocutaneous albinism need yearly eye exams along with access to refractive lenses, low vision aids and other ophthalmologic care starting from infancy.
- Parents and teachers should be aware that children with oculocutaneous albinism may face educational barriers due to health challenges, emotional challenges, discriminatory challenges and local resource limitations.
- Experiencing stigma and discrimination along with myths/superstitions about oculocutaneous albinism can have a far reaching negative psychosocial impact which can hinder a patient’s engagement in their own healthcare.

ACKNOWLEDGMENTS

The authors are grateful for the support of the American Academy of Dermatology's Skincare in Developing Countries Grant which allowed Dr Williams to initiate a sunscreen distribution program for OCA patients at Princess Marina Hospital which has been sustained by the generous ongoing support of the Lady Khama Charitable Trust. We are grateful to Malebogo Ralethaka and Lesege Ndlovu for their contribution as research assistants in this study.

DISCLOSURE

The authors have nothing to disclose.

REFERENCES

- Grønsvov K1, Ek J, Brøndum-Nielsen K. Oculocutaneous albinism. *Orphanet J Rare Dis* 2007;2:43.
- Brocco G. Albinism, stigma, subjectivity and global-local discourses in Tanzania. *Anthropol Med* 2016; 23(3):229–43.
- Brilliant MH. Albinism in Africa: a medical and social emergency. *Int Health* 2015;7(4):223–5.
- Lekalakala PT, Khammissa RA, Kramer B, et al. Oculocutaneous albinism and squamous cell carcinoma of the skin of the head and neck in sub-saharan Africa. *J Skin Cancer* 2015;2015:167847.
- Franklin A, Lund P, Bradbury-Jones C, et al. Children with albinism in African regions: their rights to 'being' and 'doing'. *BMC Int Health Hum Rights* 2018;18(1): 2.
- Opara KO, Jiburum BC. Skin cancers in albinos in a teaching Hospital in eastern Nigeria: presentation and challenges of care. *World J Surg Oncol* 2010; 8:73.
- Pooe-Moneymore MBJ, Mavundla TR, Christianson AL. The experience of people with oculocutaneous albinism. *Health SA Gesondheid* 2012; 17:1.
- Wright CY, Norval M, Hertle RW. Oculocutaneous albinism in sub-Saharan Africa: adverse sun-associated health effects and photoprotection. *Photochem Photobiol* 2015;91(1):27–32.
- Lund P, Franklin A. Albinism in East and Southern Africa knowledge based upon a descriptive literature review of research. *Foundation of Applied Research on Disability*; 2017.
- Ajose FO, Parker RA, Merrill EL, et al. Quantification and comparison of psychiatric distress in African patients with albinism and vitiligo: a 5-year prospective study. *J Eur Acad Dermatol Venereol* 2014; 28(7):925–32.
- Kiprono SK, Chaula BM, Beltraminelli H. Histological review of skin cancers in African albinos: a 10-year retrospective review. *BMC Cancer* 2014; 14:157.
- Asuquo ME, Ebughe G. Major dermatological malignancies encountered in the University of Calabar Teaching Hospital, Calabar, southern Nigeria. *Int J Dermatol* 2012;51(Suppl 1):32–6, 36–40.
- Lookingbill DP, Lookingbill GL, Leppard B. Actinic lentigenes versus skin cancer risk in albinos in northern Tanzania. *J Am Acad Dermatol* 1995;33(2 Pt 1): 299–300.
- Mabula JB, Chalya PL, Mchembe MD, et al. Skin cancers among albinos at a University teaching hospital in Northwestern Tanzania: a retrospective review of 64 cases. *BMC Dermatol* 2012;12:5.
- Phatoli R, Bila N, Ross E. Being black in a white skin: beliefs and stereotypes around albinism at a South African university. *Afr J Disabil* 2015;4(1):106.
- Baker C, Lund P, Nyathi R, et al. The myths surrounding people with albinism in South Africa and Zimbabwe. *J Afr Cult Stud* 2010;22:169–81.
- Constitution of the World Health Organization. *World Health Organization Handbook of basic documents*. 1952;5:3-20.
- Hong ES, Zeeb H, Repacholi MH. Albinism in Africa as a public health issue. *BMC Public Health* 2006;6: 212.
- Patrick DL, Bush JW, Chen MM. Toward an operational definition of health. *J Health Soc Behav* 1973;14:6–23.
- Guyatt G, Feeny D, Patrick D. Measuring health-related quality of life. *Ann Intern Med* 1993;118(8): 622–9.
- Maia M, Volpini BM, dos Santos GA, et al. Quality of life in patients with oculocutaneous albinism. *An Bras Dermatol* 2015;90(4):513–7.
- Programme on Mental Health. *WHOQOL-bref survey manual*. World Health Organization; 1996.
- Braun V, Clarke V. Using thematic analysis in psychology. *Qualitative Research in Psychology*. 2008; 3:2: 77-101.
- All-In-One Qualitative & Mixed Methods Data Analysis Tool. In: MAXQDA. 2019. Available at: www.maxqda.com. Accessed June, 2019.
- Schulze Schwering M, Kumar N, Bohrmann D, et al. Refractive errors, visual impairment, and the use of low-vision devices in albinism in Malawi. *Graefes Arch Clin Exp Ophthalmol* 2015; 253(4):655–61.
- Kirkwood BJ. Albinism and its implications with vision. *Insight* 2009;34(2):13–6.
- Penchansky R, Thomas JW. The concept of access: definition and relationship to consumer satisfaction. *Med Care* 1981;19(2):127–40.
- Tapera R, Moseki S, January J. The status of health promotion in Botswana. *J Public Health Afr* 2018; 9(1):699.

29. Letamo G. Prevalence of, and factors associated with, HIV/AIDS-related stigma and discriminatory attitudes in Botswana. *J Health Popul Nutr* 2003;21(4): 347–57.
30. Letshwenyo-Maruatona SB, Madisa M, Boitshwarelo T, et al. Association between HIV/AIDS knowledge and stigma towards people living with HIV/AIDS in Botswana. *Afr J AIDS Res* 2019; 18(1):58–64.
31. Wolfe WR, Weiser SD, Bangsberg DR, et al. Effects of HIV-related stigma among an early sample of patients receiving antiretroviral therapy in Botswana. *AIDS Care* 2006;18(8):931–3.
32. Kromberg J, Manga P. Albinism in Africa: historical, geographic, medical, genetic, and psychosocial aspects. London Academic Press; 2018.
33. Nthomang K. Botswana's ipelegeng programme design and implementation: reduction or perpetuation/entrenchment of poverty? *Asian Journal of Social Science Studies* 2018;3(3):27.
34. Republic of Botswana. Ministry of Local Government and Rural Development. In: GOV.BW. 2020. Available at: www.gov.bw/ministry-local-government-and-rural-development. Accessed April 29, 2020.
35. Masanja MM, Mvena ZSK, Kayunze KA. Albinism: awareness, attitudes and level of albinos' predicament in Sukumaland, Tanzania. *Asian Journal of Applied Science and Engineering* 2014;3(4): 382–95.
36. De Maeseneer J. Scaling up family medicine and primary health care in Africa: statement of the prima-famed network, Victoria Falls, Zimbabwe. *Afr J Prim Health Care Fam Med* 2013;5(1):61–3.
37. Freeland H. Vision program. *Standing Voice*; 2018.
38. Brandt R. The mental health of people living with HIV/AIDS in Africa: a systematic review. *Afr J AIDS Res* 2010;8(2):123–33.
39. Geiselhart K. Stigma and discrimination: social encounters, identity and space; a concept derived from HIV and AIDS related research in the high prevalence country Botswana. 2009.
40. Gilbert L, Walker L. 'My biggest fear was that people would reject me once they knew my status...': stigma as experienced by patients in an HIV/AIDS clinic in Johannesburg, South Africa. *Health Soc Care Community* 2010;18(2):139–46.
41. Leino-Kilpi H, Johansson K, Heikkinen K, et al. Patient education and health-related quality of life: surgical hospital patients as a case in point. *J Nurs Care Qual* 2005;20(4):307–16 [quiz: 317–8].
42. Ndomondo E. Educating children with albinism in Tanzanian regular secondary schools: challenges and opportunities. *Int J Educ Res* 2015;3(6): 389–400.
43. Patti F, Pozzilli C, Montanari E, et al. Effects of education level and employment status on HRQoL in early relapsing-remitting multiple sclerosis. *Mult Scler* 2007;13(6):783–91.
44. Lasheras C, Patterson AM, Casado C, et al. Effects of education on the quality of life, diet, and cardiovascular risk factors in an elderly Spanish community population. *Exp Aging Res* 2001;27(3):257–70.
45. Freeland H. Skin cancer prevention program. *Standing Voice*; 2018. p. 1–58.
46. Human Rights Council. Independent expert on the enjoyment of human rights of persons with albinism. The United Nations. 2015. Available at: <https://www.undocs.org/A/HRC/28/L.10>. Accessed March, 2020.
47. General Assembly. Social development challenges faced by persons with albinism: report of Secretary-General. The United Nations; 2017.
48. Hillman A. Q&A: An International Movement for Albinism Rights. In: *Voice by Open Society Foundations*. 2019. Available at: <https://www.opensocietyfoundations.org/voices/q-and-a-an-international-movement-for-albinism-rights>. Accessed April 18, 2020.
49. Fernandez EL, Rutka L, Aldersey H. Exploring disability policy in africa: an online search for national disability policies and UNCRPD ratification. *Review of Disability Studies: An International Journal* 2019;13(1):1–12.