


Tropical Medicine Rounds

Patterns of skin cancer and treatment outcomes for patients with albinism at Kisangani Clinic, Democratic Republic of Congo

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Abstract

Background People with albinism (PWA) are at increased risk of photodamage and skin cancer. In many parts of Africa, there is a significant lack of knowledge regarding albinism which can lead to societal stigma, discrimination, and persecution from an early age. In the Democratic Republic of Congo (DRC), there is limited clinical data on PWA and skin cancer. We aim to better understand sociodemographics, risk factors, clinical features, and outcomes of this population.

Methods Patients with a diagnosis of albinism and skin cancer presenting to Kisangani Albino Clinic were enrolled.

Results Of 205 PWA, 61 patients were diagnosed with skin cancer with a mean age of 26.5 years. Common occupations were student (45.6%) or unemployed (26.4%). Discrimination was experienced from close contacts (24.4%) and society (67.4%). A majority (88.5%) had never used sunscreen, only 4.9% used fully sun protective clothing, and 90.2% spent 4 or more hours in the sun daily. Skin cancers had a mean size of 3.8 cm and were most commonly located on the face (47.7%). Squamous cell carcinoma was the most common histopathological diagnosis. Most patients underwent excision, and 90.2% had clinical clearance of tumors at a mean follow-up of 5.7 months.

Conclusion People living with albinism in the DRC experience a high rate of nonmelanoma skin cancers at a young age and additionally face a number of psychosocial challenges. This study represents the first attempt to analyze a cohort of patients with albinism from the DRC and serves to increase awareness of this vulnerable population.

Introduction

Albinism is a rare genetic condition with a worldwide incidence of 1 in 20,000 births, but rates as high as 1 in 1,000 births are reported in certain parts of Africa. Albinism is characterized by reduced or absence of pigmentation of the hair, skin, and eyes, as a result of deficient melanin production by melanocytes. As melanin is a photoprotective pigment that absorbs ultraviolet radiation, people living with albinism (PWA) experience visual defects and are at increased risk of photodamage and skin cancer.¹ PWA in Africa have a reported 1,000 times higher risk of squamous cell carcinoma (SCC) than in the general population.² In equatorial African countries like Nigeria and Tanzania, prior research has demonstrated that PWA commonly develop nonmelanoma skin cancers on sun-exposed areas at younger ages than typically seen in Caucasian patients.^{3,4} Studies in a number of African countries have demonstrated skin cancer

diagnoses being made at advanced stages in PWA with a poor prognosis.^{2,5-8}

In many parts of Africa, there is a significant lack of knowledge regarding albinism and the specific healthcare needs of PWA, which can lead to societal stigma, discrimination, and persecution from an early age.⁹⁻¹¹ Myths and superstitions attached to albinism including fear of contagion, fear of bad luck, and the belief that sexual intercourse with PWA cures HIV/AIDS can prevent PWA from being accepted as equal members of society.^{11,12} Alarming, these myths have even led to the murder and maiming of PWA, most prominently around the Great Lakes region of central Africa.¹³

In the Democratic Republic of Congo (DRC), there is still no reliable data on the prevalence, clinical features, or clinical outcomes of PWA. Only a single case report documenting the treatment of an advanced basal cell carcinoma (BCC) in an albino patient has been published from the DRC.¹⁴ The

Cinquantenare Hospital of Kisangani, in collaboration with the Corbetta nongovernmental organization (NGO), has worked through challenging conditions and limited resources to pioneer a center offering free dermatologic care to PWA with the goal of reducing morbidity and mortality of skin cancer related deaths in the DRC. In order to gain a better understanding of the sociodemographics, risk factors, clinical presentations, and clinical outcomes of patients with albinism and skin cancer in the DRC, we have collected data from patients with albinism presenting to the Kisangani Albino Clinic from 2015 to 2018.

Materials and methods

All patients with albinism (205) who presented to the Kisangani Albino Clinic from 2015 to 2018 were evaluated for entry into the study cohort. Patients were offered full skin cancer screening exams and educated about their condition. Patients who were clinically diagnosed with a skin cancer (61 patients) were enrolled after obtaining informed consent from the patient or legal guardian for patients under 18. No patients deferred enrollment. Criteria for the clinical diagnosis of a skin cancer included skin lesions greater than 1 cm with the morphology of nodules, plaques, or tumors which had been growing for at least 1 month with the additional criteria of either scaling, erosion, ulceration, pain, or bleeding. Pathology confirmed diagnoses were only available for 22 patients because of the lack of histopathology capacity in the Kisangani region. For patients who could afford the associated healthcare costs, specimens were sent to Kinshasa for processing and evaluation by a general pathologist. For patients who could not pay and where definitive diagnosis had implications for management, formalin fixed specimens were mailed to Penn Cutaneous Pathology Services in Philadelphia, Pennsylvania, to be processed and evaluated through the support of philanthropic funding.

Consultation sheets recorded sociodemographic factors (age, gender, marital status, education, occupation, relatives with albinism, experiences of discrimination), risk factors (sunscreen usage, barriers to sunscreen use, history of skin cancer, sun exposure, usage of sun-protective clothing), clinical features (physical exam findings, tumor size, morphology, and location, histopathological diagnosis, treatment), and outcomes. All data were encoded into Microsoft Excel for descriptive analysis. Ethical approval for the completion of this study was obtained from the University of Pennsylvania Institutional Review Board and the Cinquantenare Hospital Medical Director because there is no institutional review board in this region of the DRC.

Results

Sociodemographic features

The mean age of the skin cancer cohort was 26.5 years (SD = 11.9), and 23% (14/61) of patients were younger than 18 years old. The male to female ratio was 1.1:1.0, and 76.3%

(45/59) identified as single. Of patients younger than 18 years, the majority were in either primary (42.9%), secondary (35.7%), or tertiary (14.3%) school, and one was illiterate (7.1%). Of 43 patients aged 18 and older, one (2.3%) had achieved a bachelor's degree, 20 (46.5%) reported some tertiary education (education beyond high school level), 16 (37.3%) had a secondary school certificate (graduated from high school), one (2.3%) had only reached primary school level (elementary or junior high school), and five (11.6%) were illiterate.

Overall, the majority of patients reported being either a student (45.6%, 26/57) or unemployed (26.4%, 15/57). Only 28% (16/57) had a paid form of employment. Of 56 patients with available data, 30 (53.6%) had other family members with albinism. Of 46 patients, 11 (24.4%) reported experiencing discrimination from close family or friends, and 31 (67.4%) experienced discrimination from society members. A majority of patients (88.5%, 54/61) had never used sunscreen. The reported barriers to sunscreen use were inaccessibility (48.1%, 26/54), limited understanding of the need to use sunscreen (46.3%, 25/54), and financial difficulty (35.2%, 19/54). Sixteen (29.6%) reported a combination of financial difficulty and a limited understanding of the need to use sunscreen. Most patients (90.2%) utilized some form of sun-protective clothing; however, only 4.9% used fully sun-protective clothing that covered all sun-exposed parts of the body. Nearly all participants (90.2%) reported spending at least four hours in the sun daily, and of the 16 employed participants, six (37.5%) had to work outdoors. Full demographics are detailed in Table 1.

Clinical features

The skin cancer rate at Kisangani Albino Clinic was 29.8% (61/205). Only 9.8% of patients reported a known prior history of skin cancer. On exam, patients with albinism had solar lentiginos (47.5%), skin erythema (100%), actinic keratoses (AKs) (100%), actinic cheilitis (91.8%), and predominantly white hair (85.2%). Most patients had skin erythema (96.3%) and AKs (92%) involving four or more body regions (including either the scalp, face, neck, trunk, upper extremities, and/or lower extremities). Lesions concerning for skin cancer ranged in size from 1.2 to 8.4 cm with a mean size of 3.8 cm (SD = 1.2 cm). The most common lesional morphology was ulcerated tumors in 65.8%. A range of one to nine neoplastic skin lesions were identified per patient (mean = 2, SD = 1.5). Lesion locations included the face (47.7%), scalp (10.3%), neck (6.8%), trunk (5.7%), and extremities (29.5%). Regional lymphadenopathy as a clinical sign of locoregional invasion was present in 11.5% of cases. Clinical features are summarized in Table 2.

Diagnosis and treatment outcomes

Actinic keratoses were diagnosed clinically, and only two patients were able to undergo AK directed therapy. Diclofenac gel was used for 12 weeks, and both patients had a good clinical response. Skin neoplasms were diagnosed based on clinical

Table 1 Sociodemographic features of patients with albinism at Kisangani Albino Clinic

	Frequency (n)	Percentage (%)
Gender (n = 61)		
Male	32	52.5
Female	29	47.5
Age (n = 61, Mean 26.5 ± 11.9)		
Under 18 years old	14	23
18 years or older	47	77
Marital status (n = 59)		
Married	14	23.7
Single	45	76.3
Occupation (n = 57)		
Student	26	45.6
Unemployed	15	26.4
Employed with indoor work	10	17.5
Employed with outdoor work	6	10.5
Highest level of education (≥18 years old, n = 43)		
Illiterate	5	11.6
Primary school	1	2.3
Secondary school	16	37.3
Tertiary school	20	46.5
Bachelor degree	1	2.3
Has family members with albinism (n = 56)		
Yes	30	53.6
No	26	46.4
Discrimination experienced from friends/family (n = 47)		
Yes	11	24.4
No	36	76.6
Discrimination experienced from society (n = 46)		
Yes	31	67.4
No	15	32.6
Has used sunscreen (n = 61)		
Yes	7	11.5
No	54	88.5
Barriers to use of sunscreen (n = 54, multiple answers possible, % is out of total sample)		
No access	26	48.1
Limited understanding of need	25	46.3
Financial barriers	19	35.2
Combination of financial barriers and limited understanding of need	16	29.6
Use of sun protective clothing (n = 61)		
None	3	4.9
Partial ^a	55	90.2
Complete ^b	3	4.9

^aPartial = only some sun-exposed body parts are covered.

^bComplete = all sun-exposed areas of the body covered including scalp, face, neck, trunk, upper extremities, lower extremities.

criteria with a differential diagnosis of basal cell carcinoma versus squamous cell carcinoma for all patients. Histopathological analysis could only be performed on 28 specimens from 22 patients. Diagnoses included basal cell carcinoma (35.8%, 10), squamous cell carcinoma (57.1%, 16), and squamous cell carcinoma in situ (7.1%, 2). Of the 16 SCCs examined for differentiation, three were well-differentiated, seven moderately

Table 2 Clinical features of patients with albinism at Kisangani Albino Clinic

	Frequency (n)	Percentage (%)
History of skin cancer (n = 61)		
Yes	6	9.8
No	55	90.2
Hair color (n = 61)		
White	52	85.2
Yellow	1	1.6
Red	3	5
Light brown	5	8.2
Presence of solar lentigines (n = 61)		
Yes	29	47.5
No	32	52.5
Presence of skin erythema (n = 61)		
Yes	61	100
No	0	0
Number of body regions ^a with erythema (n = 55)		
≤3	2	3.6
≥4	53	96.3
Actinic cheilitis present (n = 61)		
Yes	56	91.8
No	5	8.2
AKs present (n = 61)		
Yes	61	100
No	0	0
Number of body regions ^a with AKs (n = 61)		
≤3	5	8
≥4	56	92
AK treatment (n = 61)		
None	59	96.7
Diclofenac gel	2	3.3
Number of skin cancers clinically diagnosed per patient (n = 61)		
1	30	49.3
2–5	29	47.5
≥6	2	3.2
Clinical evidence of locoregional tumor invasion (n = 61)		
Yes	7	11.5
No	54	88.5
Location of skin cancers (n = 88 skin cancers found in 61 patients)		
Scalp	9	10.3
Face	42	47.7
Neck	6	6.8
Trunk	5	5.7
Extremities	26	29.5
Treatment (n = 61)		
Wound care	4	6.6
Excision only	55	90.2
Excision and chemotherapy	1	1.6
Excision, skin graft, and chemotherapy	1	1.6
Skin cancer histology (n = 28 specimens in 22 patients)		
SCCIS	2	7.1
SCC	16	57.1
BCC	10	35.8
SCCs examined for differentiation (n = 16 specimens)		
Well-differentiated	3	18.8
Moderately differentiated	7	43.7

Table 2 Continued

	Frequency (n)	Percentage (%)
Poorly differentiated	6	37.5
Follow-up time (months, n = 56)		
4	11	19.6
6	43	76.8
9	2	3.6
Treatment outcome (n = 61)		
Clinical clearance	55	90.2
Residual disease	1	1.6
Death	5	8.2

AK, actinic keratoses; SCCIS, squamous cell carcinoma in situ; BCC, basal cell carcinoma; SCC, squamous cell carcinoma.

^aBody regions = scalp, face, neck, trunk, upper extremities, lower extremities.

differentiated, and six poorly differentiated. Treatments included surgical excision (90.2%), excision and chemotherapy (1.6%), a combination of excision, skin grafting, and chemotherapy (1.6%), and palliative wound care (6.6%). Treatment outcomes achieved were clinical clearance in 55 patients (90.2%), residual disease in one patient (1.6%), and death in five patients (8.2%), including one patient under the age of 18. Patient deaths were attributed to complications from their advanced skin cancers. Follow-up time was available for 56 patients with a mean of 5.7 months (SD = 1.02).

Conclusions

This study represents the first attempt to analyze a cohort of patients with albinism from the DRC, where a number of local issues including political instability, armed conflicts, extreme poverty, displaced populations, and weak healthcare infrastructure make access to care for a marginalized population even more difficult. Previous studies have reported that people living with albinism (PWA) in Africa predominantly develop skin cancers by the second decade of life and do not commonly live beyond the age of 30 years.^{8,15} Lending further support to this claim, our cohort was predominantly young with a mean age of 26.5 years, and 23% of the patients were under 18 years old. In contrast, a more recent study of the albinism population in Tanzania reported a mean age of 35 years, indicating an increased survival rate for PWA.⁴ This could be due to the large-scale Albino Outreach Programs that have been implemented across Tanzania since 1993. These programs have allowed early intervention of sun protection counseling, sun protective materials, and regular skin checks which are lacking in the DRC.^{4,6}

All of our patients had significant actinic damage evidenced by skin erythema and AKs covering at least four body regions in most patients. Actinic cheilitis was also a prominent feature in over 90%. Treatment interventions for AKs were only available

for two patients because of the high cost of topical chemotherapies and no local access to cryotherapy. Without options for treatment of AKs, PWA in the DRC are at high risk for continued development of actinic damage and SCCs.

The skin cancer prevalence was 29.8% in our cohort, and patients were more likely to present with multiple neoplastic lesions, ranging up to nine per patient. Most patients had large ulcerated tumors which averaged 3.8 cm but reached up to 8.4 cm in size. Additionally, a number of patients had large destructive tumors with signs of locoregional invasion suggesting a poorer prognosis (Fig. 1). The most common locations were the face, neck, scalp, and extremities, which is consistent with the extensive sun exposure reported by patients. Histopathology was only available for 28 of 88 specimens because of the cost associated with sending samples to the capital (Kinshasa) or out of the country, which are the only two options for obtaining histological analysis from Kisangani Albino Clinic. All malignancies were nonmelanoma skin cancers, with SCC followed by BCC as the most frequent, and this is consistent with the prevalence patterns of nonmelanoma skin cancers reported for PWA in other African countries.^{3,4} Of examined cases, 37.5% were poorly differentiated SCCs, which is significantly higher than the 6.9% frequency of poorly differentiated SCCs found in a cohort of 134 tumors from PWA in Tanzania.⁴ This may indicate that PWA in the DRC are presenting with more advanced and/or aggressive SCC tumors. However, our small sample size limits the ability to generalize this data. Additionally, data were not available for the length of time that skin lesions were noticed before patients received a diagnosis of skin cancer to determine the time course of progression and contribution of treatment delays. Future studies are needed to evaluate associated risk factors contributing to the development of numerous, large sized, and invasive skin tumors in PWA in the DRC.

Numerous sun-related risk factors for skin cancers were uncovered in our cohort. Most importantly, 88.5% of patients had never used sunscreen. The greatest reported barrier to sunscreen usage was complete lack of access in this region of the DRC, meaning even those who could afford to purchase it could not find sunscreen available to buy. Many African countries have limited sunscreen products stocked in local shops, presumably because historically there has been a low demand for sunscreen from African populations. Sunscreen is particularly difficult to find in rural areas like Kisangani, where access to consumer products in general is less than in urban areas. Sunscreen is also relatively expensive, and 35.2% of our cohort confirmed that finances created a barrier to usage. Significantly, 46.3% did not even understand the need for sunscreen, which highlights a critical gap in sun protection knowledge that exists among PWA in the DRC.

Our data indicates that excessive sun exposure was a significant problem faced by this cohort. The majority of patients (90.2%) spent at least four hours in the sun daily, and of the

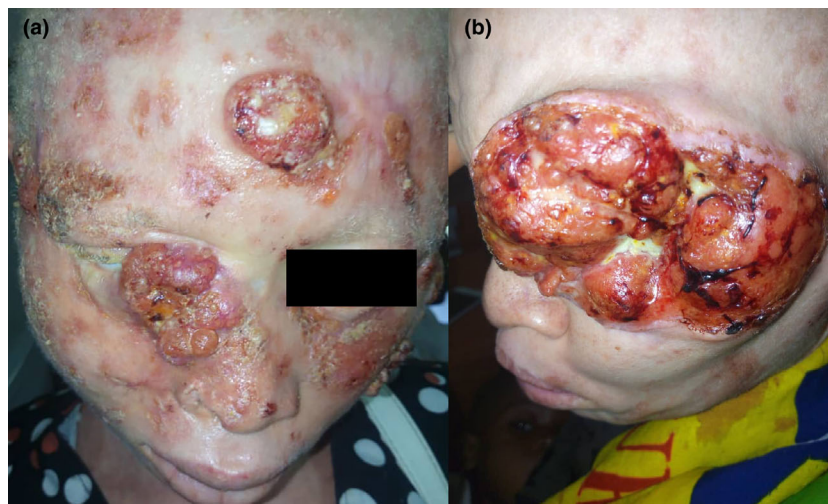


Figure 1 Two patients with albinism treated at Kisangani Albino Clinic for (a) multiple eroded squamous cell carcinoma tumors on the face with invasion into the right orbit and a background of severe actinic damage. (b) A large eroded squamous cell carcinoma tumor with invasive destruction of the underlying structures of the left temple, cheek, nose, and orbit.

employed patients, 10.5% were required to work outside. Although most (90.2%) patients attempted some form of partial sun protection, very few (4.9%) were correctly utilizing fully sun-protective clothing, which further supports a hazardous gap in knowledge around sun protection. Similarly, a previous report from neighboring Tanzania found that 50% of PWA spent over six hours per day in the sun, 62% did not wear a hat, and 80% felt the need to wear short-sleeved clothing because of the discomfort of working outdoors in hot weather conditions.^{4,16} Interventions aimed at improving access to sunscreen, sun-protective clothing, and education on both the need for sun protection and effective sun protection techniques are critically needed to reduce skin cancer incidence in this patient population. Additionally, to realistically allow PWA to maintain sun protective behaviors, it will be important for local economies to develop job opportunities suited to the needs of PWA with, for example, programs to build skills compatible with indoor employment.

Surgical excision was the mainstay of treatment for skin cancers, but two patients were able to receive chemotherapy, and one patient underwent a partially successful skin graft. The Kisangani Albino Clinic is staffed by one physician trained with a six-month certificate course in dermatology from the Regional Dermatology Training Center (RDTC) in Moshi, Tanzania (author GI, Fig. 2). Even with limited surgical training and minimal equipment, this clinician achieved clinical clearance in 90.2% of patients with skin cancer at a mean follow-up time of 5.7 months. This illustrates the positive impact that short-term dermatology training programs can have to improve dermatology care for underserved populations. In the DRC, there are a number of practicing dermatologists; however, their clinics are located near the capital city of Kinshasa. Specialist physicians tend to cluster around urban centers where job opportunities are more plentiful and lucrative. This trend leaves a huge gap in care, especially in underdeveloped countries, like the DRC, where much of the population lives rurally. Shorter

nonresidency/nonmasters training programs, like the RDTC's Diploma in Dermatology, offer a key mechanism for increasing dermatology access. They equip medical officers with practical dermatology skills, and there is an understanding that physicians will return to serve their local region as a "community" dermatologist. Kisangani Albino Clinic is a leading example of the success of this model. It represents the only dermatology expertise available for the entire eastern region of the country and is being successfully run by a community dermatologist.

The medical challenges faced by PWA in our cohort were compounded by psychosocial difficulties. The majority of patients (72%) were unable to earn an income because of being either a student or unemployed, which can have a major impact on financial access to healthcare, sunscreen, and sun-protective clothing. Over half (51.2%) of adult patients had a secondary school or lower level of education. Prior studies of PWA in other parts of Africa have demonstrated similarly low levels of education, thought to be due to visual challenges hindering successful learning.⁹ Without the education or skills to qualify for higher paying indoor work, often the only possibility left for PWA is to take low-paying jobs as outdoor laborers and jeopardize their health with extensive daily UV exposure.¹⁶

Previous studies have revealed that discrimination and stigma are major challenges in the day-to-day life of PWA in various regions of Africa.⁹⁻¹¹ Societal discrimination of PWA is also highly prevalent in the DRC and was reported by 67.4% of patients. Surprisingly, 24.4% of patients experienced discrimination from their own close family and friends, even when they were not the only PWA in their family. Discrimination can have far-reaching effects, limiting the ability of PWA to properly engage in education, social relationships, and healthcare.⁹⁻¹¹ In comparison, PWA in South Africa have reported better health and increased self-esteem when governmental and nongovernmental institutions were able to provide reliable educational, social, and medical resources.^{9,17,18} Campaigns are needed to increase albinism awareness

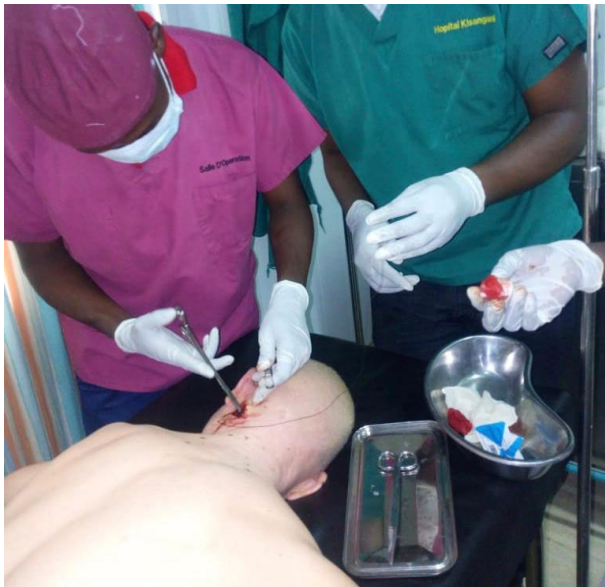


Figure 2 Dr. Gaylord Inena performing a surgical excision of a basal cell carcinoma on the posterior neck of a patient with albinism at Kisangani Albino Clinic.

among the general population in the DRC and promote inclusivity of PWA into society.

Limitations of this study include the small sample size, limited follow-up period, and incomplete data including lack of histological diagnosis for many cases. The limited access to diagnostic histopathology in our cohort is a common barrier to cancer care across sub-Saharan Africa.¹⁹ Telemedicine can provide innovative solutions to increase access to histology and other vital diagnostic services.²⁰ We utilized telepathology which can include remote sharing of slide images or, for regions such as ours which lack histology services, formalin fixed tissue specimens can be sent to experienced laboratories for processing and analysis.²¹

This study is an important first step to describe PWA with skin cancer in the DRC, and it serves to increase awareness of the important psychosocial and medical challenges they face. Our cohort experienced late cancer diagnoses with associated morbidity and mortality which may be due to a myriad of risk factors including poverty, low education, and lack of access to healthcare with huge distances needing to be traveled to even reach a dermatology provider. These risk factors are likely compounded in the DRC because of the instability of local economic, infrastructure, government, and social welfare resource systems. However, the achievement of clinical clearance in 90.2% of skin cancer patients in this cohort demonstrates the impact that a small dedicated albinism clinic can make on a neglected patient population. Future studies are needed to further characterize skin cancer risks for PWA in the DRC on a larger scale with detailed epidemiological, clinical and long-term follow-up data.

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