

Education

Evaluation of the acceptance and efficacy of a bespoke sun protection package for persons with oculocutaneous albinism living in Malawi

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Introduction

Oculocutaneous albinism is a group of rare inherited disorders of pigmentation. Its prevalence in Africa ranges from 1/5,000 to 1/15,000.¹ Skin cancer is the main cause of death in persons with albinism (PWA) in Africa. Many PWA develop advanced skin cancers in the third to fourth decade of life.^{2,3} Measures to minimize sun damage are necessary to prevent avoidable deaths. These include: sun avoidance, wearing sun protective clothing, and regular application of sunscreens⁴ as well as regular clinical review to detect and treat early skin cancers. Providing comprehensive photo-education services and cosmetically

Abstract

Introduction Skin cancer is the main cause of death in persons with albinism (PWA) in Africa. Education would minimize sun damage.

Objective To evaluate the efficacy and acceptance of a photoprotection educative and sunscreen (Umozi Max) package designed for PWA in reducing sunburns and skin cancer.

Patients and Methods A multicenter, noncontrolled, before-and-after, interventional study was conducted in PWA > 12 years of age, from February to May, 2019, in Malawi. During the baseline and the follow-up visits (at 8 and 15 weeks), subjects received an educational program designed to PWA and use of Umozi Max. At every visit, photoprotection behavior and knowledge were checked and cutaneous lesions were recorded. Univariate and bivariate analysis were performed.

Results A total of 210 PWA were analyzed, 50% males, with a mean age of 24.5 (SD 11.29) years. The percentage of people using sun protective clothing increased from 80% to 100% and sunscreen from 81.9% to 99.5%. People avoiding the midday sun increased by 38.9% ($P < 0.05$). Participants that erroneously applied the sunscreen at night diminished from 40% to 4% ($P < 0.001$). Absent erythema on the face increased from 40% to 90% ($P < 0.05$). The percentage of patients with actinic keratoses (AK) on all locations significantly decreased during the study. All the participants preferred Umozi Max to previously used sunscreens. The satisfaction with the program was unanimous.

Conclusion The educational program enhanced the use of all photoprotection measures, improved behaviors, and decreased the incidence of solar erythema and contributed to decreasing the incidence of new AKs.

acceptable sunscreens that PWA like to wear are key to ensuring compliance, one of the most important factors for optimal ultraviolet (UV) protection.

Regular use of broad-spectrum sunscreens has been shown to reduce photoaging and skin cancer risk, especially squamous cell carcinoma, the most common type of skin cancer in PWA in Sub-Saharan Africa.⁴⁻⁸

The objective of this study was to evaluate the efficacy and acceptance of a sun protection package tailored for PWA in Malawi to reduce the incidence of sun-induced skin lesions. In

addition, the study evaluated the preference, acceptability, and adherence to Umozi Max, a sunscreen developed considering the preferences of people with albinism in Africa.

Participants and methods

Population of the study

A multicenter, noncontrolled, before-and-after, interventional study was conducted from February 4 to May 24, 2019, in Malawi. Patients from three different environments, urban, semi-urban, and rural areas, were included. Four clinics were conducted in four outreach sites in four different districts. All PWA older than 12 years were invited to participate by the District Health Officer and the Association of Persons with albinism in Malawi (APAM). Exclusion criteria included being unable to return for follow-up visits within the study period; people with mental disorders or who were too ill were excluded because this could introduce a bias in the accomplishment of the study and, in consequence, in the results.

Sample size was calculated based on the main result variable of the study, the presence of sunburn. Accepting the efficacy of the intervention in producing a reduction of 15% of this variable, to achieve a power of 80% and the confidence level of 95%, 200 subjects were required.

Protocol

During the first visit, informed consent was obtained and baseline information (sun protection habits, knowledge, etc.) collected using a questionnaire (Supplementary Material). This was a validated questionnaire in Spanish,⁸ translated into English and Chichewa by translators, and review by dermatologists from Malawi; this was also pretested with the local team of dermatologists and clinicians involved in the implementation of the study, and minor adaptations were done and approved by the investigators. During the baseline and the two follow-up visits, study participants received an interactive group education event aimed at three areas: (1) Improving understanding about the origin of albinism (helping to clear misconceptions); (2) Highlighting the deleterious effects of sun exposure, reinforcing its role in the development of skin cancer; and (3) Clarifying photoprotection measures with special emphasis on the adequate use of sunscreen. The relationship between sun exposure and photoaging of the skin was also emphasized.⁹

Later, they received the full educational program divided into three sections: understanding albinism; sun protection and skin cancer; and use of Umozi Max.

Umozi Max is sun protection factor (SPF) 50+, broad spectrum, high water-resistant sunscreen specially designed for PWA living in Sub-Saharan environments. Umozi Max has passed all relevant efficacy, tolerant, and stability tests. The active ingredients are Bis-Ethylhexyloxyphenol Methoxyphenyl Triazine, Ethylhexyl Triazone, Methylene Bis-Benzotriazol Tetramethylbutylphenol, and TrisBiphenyl Triazine. The preservative used in the formulation is

a blend of benzyl alcohol & dehydroacetic acid, featuring dehydroacetic acid as the primary active ingredient. The investigator provided each participant with a 225 ml jar of Umozi Max, a suitable quantity for a 2-month supply for one person, according to our experience of sunscreen consumption of a PWA in Tanzania.

Full physical examination was performed and the number and sight of cutaneous lesions recorded at every visit (at 8 and 15 weeks). Solar-related changes detected such as erythema, actinic keratoses, and skin cancer were recorded and treated by the dermatology clinical officer or dermatologist. Patients were transferred to the referral hospital when further management was required. Information regarding the acceptance of the sunscreen and the satisfaction with the program (questionnaire in Supplementary Material) was also collected.

All protocol was performed by the dermatologists who conducted the study; they explained the informed consent, asked and explained the questions of the questionnaire, and carried out the physical examination.

Measurement of outcomes

The primary outcome measure was the reduction in the incidence of solar erythema and number of actinic keratoses. Secondary outcomes included: changes in the use of sunscreen and appropriate clothing; avoidance of midday sun; acceptability of the new Umozi Max sunscreen along with the undesired effects; acceptance and satisfaction with the educational program as well as the improvement of their understanding of albinism, sunscreen use, and photoprotection.

Statistical analysis

A descriptive analysis was carried out presenting the qualitative variables as proportions and the quantitative variables as means and standard deviations. The bivariate analysis included chi squared for paired samples (McNemar test) for qualitative variates and paired *t* test for quantitative variates. SPSS ver 24 (IBM Corp., Armonk, NY) was used for the statistical analysis. Statistical significance was considered when $P < 0.05$.

Ethics

Written informed consent was sought from all participants, and ethical approval was obtained by the Malawian National Committee on Research in the Social Sciences and Humanities in December 2018 (P.11/18/329).

Results

Study population: demographic characteristics and skin cancer risk factors

Table 1 shows the characteristics of the study population. Two hundred fifty-nine patients responded to the invitation to participate in the study, and all of them wanted to be recruited. Forty-nine were excluded due to incomplete follow-up or significant errors in the questionnaires. Data of 210 participants were analyzed, 50.5%

Table 1 Demographic characteristics of the sample

Variables	N (%)
Gender	
Male	106 (50.5)
Female	104 (49.5)
Age (median, P ₂₅ ,P ₇₅) years	23 (P ₂₅ : 15, P ₇₅ :31) Range: 10–65
Region	
Central	207 (98.6)
Northern	2 (1.0)
Southern	1 (0.5)
District	
Dedza	49 (23.3)
Lilongwe	55 (26.2)
Mangochi	1 (0.5)
Mchinji	2 (1.0)
Mzimba	1 (0.5)
Nkhotakota	30 (14.3)
Ntcheu	49 (23.3)
Ntchru	1 (0.5)
Rumphi	1 (0.5)
Salima	21 (10)
Education level	
College/University	14 (6.7)
No school	6 (2.9)
Primary	136 (64.8)
Secondary	54 (25.7)
Relatives	
No	75 (35.7)
Yes	135 (64.3)
Previous squamous cell carcinoma	
No	188 (89.5)
Yes	18 (8.6)
Unknown	4 (1.9)
Current use of sunscreen	
No	30 (14.28)
Yes	172 (81.90)
No answer	8 (3.81)
SPF used	
30	70 (33.3)
50	72 (34.3)
Unknown	30 (14.3)
No answer	38 (18.1)
Name of sunscreen	
Biocare	13
Lemon oil	0
Life care	1
Max Block	0
Nivea	8
Protect	1
Protect Sun	2
Sunblock	28
Suncream	1
Sunkids	1
Sun Ozon	1
Sunprotect	1
Sunscreen	0
Sunscreen oil	1
Zanca	1
Zinc	2
Other	1
No answer	132

male and 49.5% women, with a mean age of 24.5 years (SD 11.29, range 12–65). Most of them (98.6%) were from the Central region of Malawi. Sixty-five percent did not finish Primary school or stopped schooling after it, and only 6.7% had University studies. Eighteen (8.6%) had a history of skin cancer.

Impact of the educational program on the photoprotection behaviors and attitudes

Table 2 summarizes the impact of the educational program on photoprotection behaviors. There was a 38.9% improvement in subjects reporting that they “always” or “almost always” avoided the midday sun ($P < 0.003$).

Regarding sunscreen use at baseline, the majority reported using it (81.9%); however, after the program, this increased to 99.5%. Additionally, there was an improvement in the sunscreen application technique. At baseline, 40% of participants erroneously applied the cream in the evening. This decreased to 4% at the end of the study ($P < 0.001$). The use of sunscreen on the face (89%), lips (79%), neck (91%), ears (89%), and upper limbs (92.4%) increased to 99–100% at the end of the final follow-up ($P < 0.05$). A reduction in its use on the legs was observed (from 88.1% to 76.2%), although the differences were not statistically significant ($P = 0.5$).

The use of full photoprotective clothing (long sleeves and wide-brimmed hat) increased from baseline (80–90%) to 99–100% at the last follow-up visit.

All the questions addressing attitude to sun protection improved along the follow-up apart from the question “I worry about getting sunburned when I am exposed to the sun”; this could be explained by an increase in their confidence on their sun protection measures (Fig. 1). At the last visit, all the participants correctly answered questions relating to photoprotection except for 2% incorrectly responding to the question related to the sun protection effect of clothing color (Fig. 2).

Evaluation and acceptance of the sunscreen UMOXI MAX

All the participants preferred Umozi Max to previously used sunscreens, with 99.5% reporting daily application of the cream. Only two participants noted adverse effects from the sunscreen. Both reported redness of the skin, and one also reported blisters. One of the patients subsequently resumed use without side effects. Neither patient was reviewed by a physician. The amount of Umozi Max required to cover the needs of one person with albinism for 2 months was 225 ml.

Impact of the program in the clinical signs of acute and chronic sun damage

The incidence of facial erythema reduced from 60% at baseline to 10% of the participants at the last visit ($P < 0.05$) (Fig. 3).

Sixteen percent of the participants had AK at baseline on the face, 16.8% on the lips, 20.5% on the lower limbs, 23.4% on the neck, and 33.3% on the upper limbs. All were treated with cryotherapy. At the end of the follow-up, the percentage of patients with AK fell from 3.3% to 1% for the five body areas (Table 3).

Table 2 Impact of the program in the photoprotection habits

	Enrollment	Follow-UP2	P*	Follow-UP3	P**
Current use sunscreen			0.446		
No	30 (14.27)	4 (0.02)			
Yes	172 (81.90)	206 (98.08)			
No answer	8 (0.03)	0			
SPF use					
30	70 (33.33)	7 (3.33)			
50	72 (34.28)	7 (3.33)			
Not known	30 (14.28)	4 (1.90)			
No answer	38 (18.09)	192 (91.42)			
Sunglasses use			0.2		<0.001
No	173 (82.4)	182 (86.7)		192 (91.4)	
Yes	37 (17.6)	28 (13.3)		18 (8.6)	
Daily sun hours (mean, SD)	3.02 (2.06)	2.50 (0.13)	<0.001	2.52 (1.57)	<0.001
Avoid sun midday			0.003		0.001
Almost always/always	128 (61.0)	167 (79.5)		179 (85.2)	
Almost never/never	12 (5.7)	40 (19.0)		30 (14.3)	
Sometimes	70 (33.3)	3 (1.4)		1 (0.5)	
Apply sunscreen morning			<0.001		<0.001
No	21 (10)	4 (1.9)		1 (.5)	
Yes	189 (90)	206 (98.1)		209 (99.5)	
Apply sunscreen afternoon			<0.001		<0.001
No	72 (43.3)	28 (13.3)		14 (6.7)	
Yes	138 (65.7)	182 (86.7)		196 (93.3)	
Apply sunscreen evening			<0.001		<0.001
No	125 (59.5)	184 (87.6)		201 (95.7)	
Yes	85 (40.5)	26 (12.4)		9 (4.3)	
Additional applications			0.329		0.676
No	197 (93.8)	207 (98.6)		203 (96.7)	
Yes	12 (5.7)	3 (1.4)		7 (3.3)	
No answer	1 (0.5)	0		0	
Uses sunscreen					
Yes	199 (94.8)	210 (100)		210 (100)	
No	11 (5.2)	0		0	
Photoprotection use for areas					
Sunscreen face			0.016		
No	22 (10.5)	10 (4.8)		1 (0.5)	
Yes	187 (89.0)	200 (95.2)		209 (99.5)	
No answer	1 (0.5)	0		0	
Sunscreen lips			<0.001		<0.001
No	43 (20.5)	9 (4.3)		2 (1.0)	
Yes	166 (79.0)	200 (95.2)		207 (98.5)	
No answer	1 (0.5)	1 (0.5)		1 (0.5)	
Sunscreen neck			0.038		
No	18 (8.6)	9 (4.3)		0	
yes	191 (91.0)	201 (95.7)		210 (100)	
No answer	1 (0.5)	0		0	
Sunscreen ears			0.04		
No	22 (10.5)	9 (4.3)		0	
Yes	187 (89)	201 (95.7)		210 (100)	
No answer	1 (0.5)	0		0	
Sunscreen lower limbs			0.185		0.500
No	24 (11.4)	68 (32.4)		50 (23.8)	
Yes	185 (88.1)	142 (67.6)		160 (76.2)	
No answer	1 (0.5)	0		0	
Sunscreen upper limbs			0.021		0.069
No	15 (7.1)	8 (3.8)		1 (0.5)	
Yes	194 (92.4)	202 (96.2)		209 (99.5)	

Table 2 Continued

	Enrollment	Follow-UP2	P*	Follow-UP3	P**
No answer	1 (0.5)	0		0	
Clothes face			<0.001		0.036
Full	126 (60.0)	166 (79.0)		193 (91.9)	
None	52 (24.8)	21 (10.0)		9 (4.3)	
Partial	31 (14.8)	23 (11.0)		8 (3.8)	
No answer	1 (0.5)	0		0	
Clothes lips			<0.001		0.005
Full	124 (59.0)	172 (81.9)		194 (92.4)	
None	59 (29.1)	20 (9.5)		9 (4.3)	
Partial	26 (12.4)	18 (8.6)		7 (3.3)	
No answer	1 (0.5)	0		0	
Clothes neck			<0.001		0.030
Full	127 (60.5)	168 (80.0)		194 (92.4)	
None	56 (26.7)	22 (10.5)		7 (3.3)	
Partial	26 (12.4)	20 (9.5)		9 (4.3)	
No answer	1 (0.5)	0		0	
Clothes ears			<0.001		0.046
Full	133 (63.3)	169 (80.0)		194 (92.4)	
None	55 (26.2)	25 (11.9)		8 (3.8)	
Partial	21 (10.0)	16 (7.6)		7 (3.3)	
No answer	1 (0.5)	1 (0.5)		0 (0.5)	
Clothes lower limbs			0.000		0.146
Full	149 (71.0)	188 (99.5)		205 (97.7)	
None	1 (0.5)	2 (1.0)		0	
Partial	59 (28.1)	19 (9.0)		4 (1.9)	
No answer	1 (0.5)	1		1	
Clothes upper limbs			0.123		0.286
Full	158 (75.2)	170 (80.9)		207 (98.6)	
None	1 (0.5)	4 (1.9)		0	
Partial	50 (23.8)	35 (16.7)		3 (1.4)	
No answer	1 (0.5)	1 (0.5)		0	

Acceptance of the program

All of the participants expressed satisfaction with the program; they felt more accepted by their communities after participating in the program and would recommend the services as well as the sunscreen to others. They all reported that it improved their appearance as well as their overall skin health. Participants also described a reduction in their worries about their condition as well as an increase in self-confidence. Finally, all of them confirmed that their sun protection behavior changed as a result of the education received and that the package was acceptable in terms of time enabling them to achieve the measures without encroaching on their daily work or activities.

Discussion

The results of the study show that the bespoke educational program for PWA performed in 15 weeks was sufficient to result in an important clinical reduction in the incidence of sun-induced skin lesions. It also led to a significant improvement in sun protection attitudes, behaviors, and knowledge, as well as self-confidence.

The mean age of 24.5 years in our study aligns with the mean ages reported in previous studies^{3,10,11} even having not included

patients below 12 years of age. The young mean age of the study participants in this and previous studies may be due to several factors: (1) the youthful population of Malawi (66.8% have less than 24 years and only 2.6% have 65 or more); and (2) the low expectancy of life of persons with albinism in Malawi with many dying before reaching the age of 40 due to skin cancer.²

While it is encouraging that almost 80% of the participants used sunscreen at baseline, more than 40% were applying it in the evening, when it would be less effective. By the end of the study, there was a significant improvement in understanding of the risks of sun exposure, an alignment between the knowledge acquired and the habits and attitudes toward the sun.¹² A reduction in the use of sunscreen in the lower limbs was observed (from 88.1% to 76.2%), although the differences were not statistically significant. However, this could be explained by an increase in the use of long clothing to cover the lower limbs (from 71% to 97.7%).

We acknowledge that our participants had relatively good baseline photoprotection habits. This may have been due to them mainly coming from urban and semiurban areas with more access to education. To our knowledge, this is the first study in a tropical environment that investigates photoprotection in

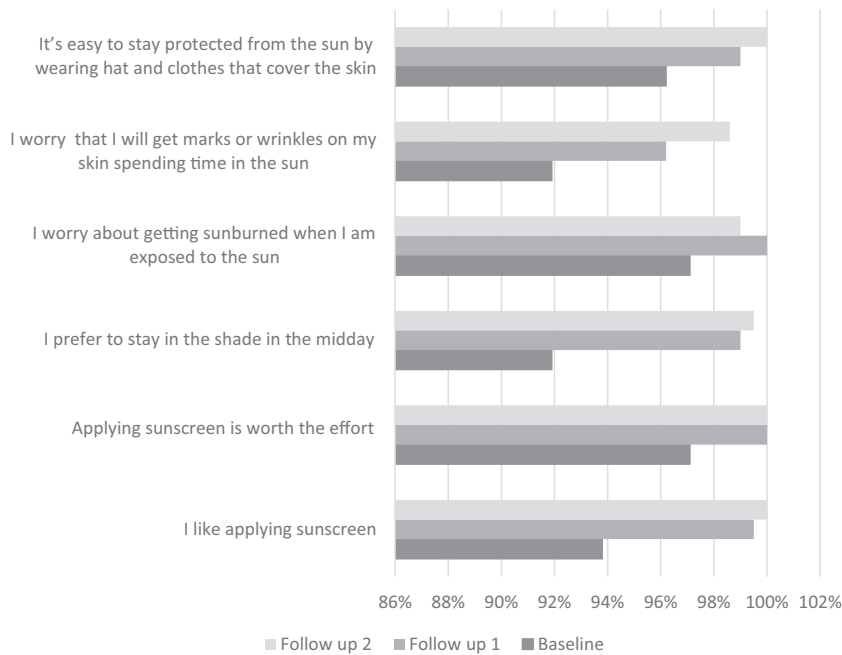


Figure 1 Evolution of the responses related to sun-protection attitude

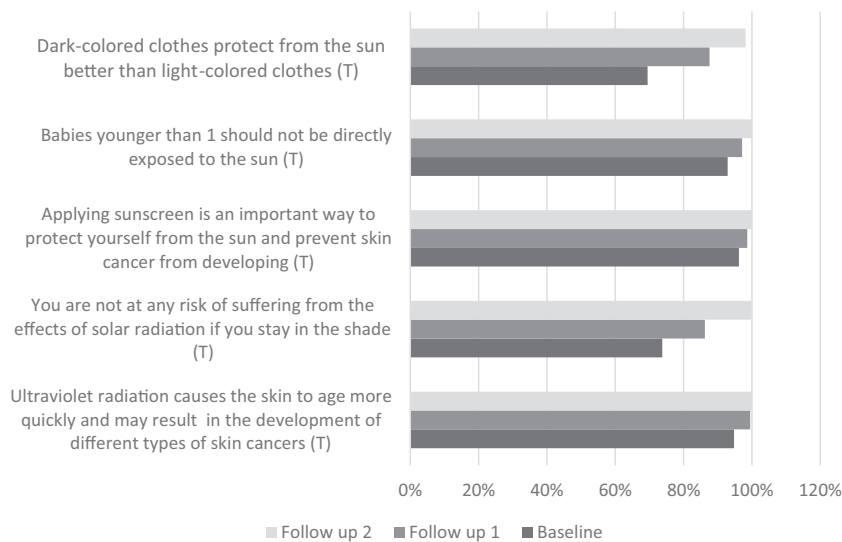


Figure 2 Evolution of the responses related to sun-protection knowledge

patients with albinism. A single study has been performed in France and involved 21 adults and 16 children using a standardized questionnaire based on a xeroderma pigmentosum photoprotection scale.¹³ The majority of these patients reported using a long-acting sunscreen Daylong, which can be applied just once a day; very few patients reported sunburn, supporting a satisfactory sun protection level. Given the higher ultraviolet index (UVI) in Africa compared to France, it is not surprising that the results are different. Much stricter photoprotection measures are needed in our study environment in order to effectively prevent skin cancer.

The most important factors influencing the impact of sunscreens are the quantity applied (71% impact) and the uniformity of the application (21% impact).^{4,14} Education to optimize application techniques with follow-up to clarify compliance are as important as its provision. Nonadherence increases to 70% if treatment regimens are complicated and/or require lifestyle changes and modification of existing habits.^{15,16} For this reason, the provision of cosmetically pleasing formulations that PWA like to wear is a key element to ensure compliance, the most important key factor for optimal UV protection.¹⁷ The participants of the study confirmed that they very much liked the

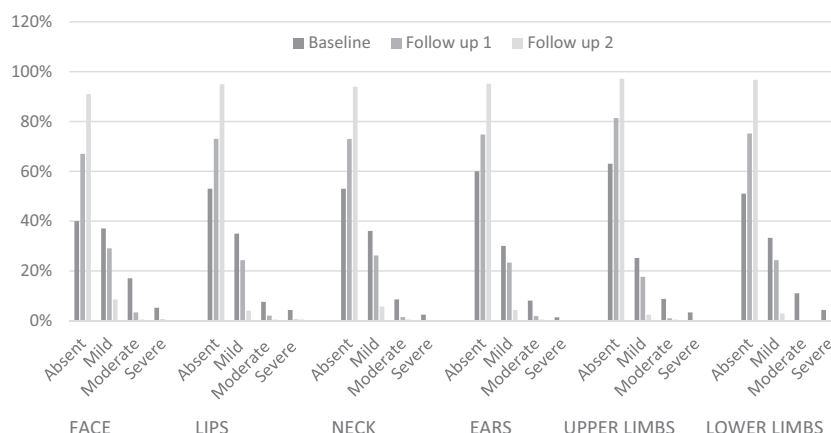


Figure 3 Impact of the program in the presence of erythema

Table 3 Impact of the program on the number of actinic keratoses

	Enrollment	Follow-up 2	Follow-up 3	P
Face				
Absent	172 (81.9%)	196 (93.3%)	203 (96.7%)	0.047**
Present	34 (16.2%)	11 (1.4%)	4 (1.9%)	
Unknown	4 (1.9%)	3 (5.2%)	3 (1.4%)	
Lips				
Absent	173 (82.2%)	207 (98.6%)	208 (99.0%)	0.001*
Present	35 (16.8%)	3 (1.4%)	2 (1.0%)	
Unknown	2 (1%)	0 (.0%)	0 (0%)	
Neck				
Absent	160 (76.20%)	191 (91.0%)	204 (97.1%)	<0.001*
Present	49 (23.4%)	19 (9.0%)	5 (2.4%)	
Unknown	1 (.1%)	0 (.0%)	1 (.1%)	
Upper limbs				
Absent	139 (66.2%)	187 (89.0%)	205 (97.6%)	0.001*
Present	70 (33.3%)	22 (10.5%)	4 (1.9%)	
Unknown	1 (0.5%)	1 (0.5%)	1 (0.5%)	
Lower limbs				
Absent	166 (79.0%)	204 (97.1%)	207 (98.6%)	0.045*
Present	43 (20.5%)	6 (2.9%)	1 (.5%)	
Unknown	1 (.5%)	0 (.0%)	2 (1.0%)	

P corresponds to the association between baseline and follow-up 1 visits* or baseline and follow-up 2 visits**.

feel of the sunscreen on their skin. They knew that the cream was specially designed for them and labeled in their local language, Chichewa. These factors may well have contributed to their preference over the less "customized" creams.¹⁸ Another advantage of Umozi Max is its safe formulation, for humans and for the environment.^{19–24} Umozi Max contains less than 1% of the preservative benzyl alcohol, minimizing its skin sensitizing potential.^{25,26} Two of the participants mentioned adverse effects related to the application of Umozi Max; neither of them were evaluated clinically as they had stopped the sunscreen application several days before the follow-up visit. Further clinical evaluation would be needed to determine cause.

The estimated annual cost of Umozi Max was 34.5 € (a package of 225 ml costs 5.75 €). This is a very low cost considering the characteristics of the product (SPF 50+, UVA-PF *in vitro*: 19.9, high water resistance, and high safety and performance UV filters) and also cheaper than the already commercialized sunscreens in the country. In addition, the high-performance formulation of this sunscreen has been designed and developed to be produced in a local manufacturing unit which would therefore ensure cheap and regular supplies in a sustainable manner.

The program has demonstrated a positive effect not only on photoprotection and understanding of albinism but also on the psychosocial aspects of the participants. Skin cancer in people with albinism is not merely a health issue but a result of the social disconnection, stigma, and discrimination experienced by PWA due to ignorance of their condition.²⁷ The education provided in the clinics has a component of "understanding albinism" where the genetics of albinism are explained, demystifying the condition, reducing the stigma attached, and improving self-esteem of PWA. Additionally, all patients considered that their skin health improved after being enrolled in the program. It also decreased their worries about albinism and increased their self-confidence. Finally, all of them confirmed that their sun protection behavior improved following the education received without investing excessive time or limiting their daily work or activities.

This is the first time an intervention program aimed at PWA in East Africa has been evaluated and shown to be effective. Information about other programs has been reported, but impact and efficacy have not been deeply studied or published.¹² Our results support the adoption and expansion of the program to other PWA communities.

Developing continuity for this type of educational intervention is key to ensure benefit.²⁸ A potential strategy is to involve "trained" patients in the education of new PWA, that is, those who have attended the sessions previously and have done well. In addition, awareness regarding effective sun protection behavior should start in childhood,²⁹ and exploring the adaptation of this educational program for children is a future priority.

The limitations of the present study include that, even though all the people with albinism from any area of the country were invited to participate in the study, the sample was more from urban and semiurban than expected, therefore, we are working on an extension of the program to all the settings (rural, semiurban, and urban). In addition, the basal percentage of using sunscreen was higher than 80% in our sample, which suggests that our population was already well disposed toward a photoprotection program, which could be introduced and internal bias in our study. Finally, the duration of the study was too short to evaluate the full potential impact of the program in its ability to lead to the reduction in the development of new skin cancers. Ideally, a longer period of follow-up would be needed to measure the reduction of skin cancer in this PWA population. The participants were included from February to May 2019 in Malawi in the southern hemisphere where the UVI is higher in February than in May. The higher the UVI, the higher the risk of sunburn. It could have caused bias in the follow-up and assessment of solar erythema and sun protection. Another limitation is that children under 12 were not included. Adapting the education messages for children under 12 and designing a similar study for them would be a next step. Finally, people with albinism with mental disorders or severe illnesses were excluded for methodological reasons; however, these persons will be also included when the program is extended.

In conclusion, the educational program, delivered in three subject sections (understanding albinism; sun protection and skin cancer; and sunscreen use) enhances the use of all photoprotection measures, improves behaviors and understanding, and decreases the incidence of erythema and new actinic keratoses. The program was well accepted, having a positive impact in the psychosocial wellbeing of persons with albinism.

Finally, the tailor-made sunscreen Umozi Max was popular, effective in the short term at reducing the occurrence of erythema and also the numbers of new AK developed, and very well tolerated.

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Supporting Information

Additional Supporting Information may be found in the online version of this article:
Supplementary Material.