

# Sociodemographic features of a cohort of people living with albinism in Botswana



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**Background:** Oculocutaneous albinism is disproportionately prevalent in Africa; however, the medical and psychosocial characteristics of people living with albinism (PWA) in Botswana have not been studied.

**Objective:** To characterize the demographics, health-related factors, sun-protective behaviors, and psychosocial challenges of PWA in Botswana.

**Methods:** Overall, 50 PWA and 99 patients without albinism (non-PWA) were recruited and surveyed.

**Results:** Higher proportions of PWA lived in rural villages compared with non-PWA (odds ratio [OR], 2.59; 95% confidence interval [CI], 1.26-5.34). PWA reported limited access to health care more frequently compared with non-PWA (OR, 2.72; 95% CI, 1.11-6.62). High proportions of PWA adopted sun-protective measures, including sunscreen, clothing, and sunlight avoidance. Despite high rates of feeling accepted by family and peers, PWA had increased odds of feeling unaccepted by their community (OR, 15.16; 95% CI, 5.25-31.81), stigmatized by society (OR, 9.37; 95% CI, 3.43-35.62), and affected by stigma in social interactions (OR, 2.21; 95% CI, 1.08-4.54) compared with non-PWA. Three-quarters of PWA had witnessed mistreatment of PWA.

**Limitations:** Study limitations include the small sample size, convenience sampling, and a non-validated survey instrument.

**Conclusion:** PWA faced increased medical and psychosocial challenges compared with non-PWA in Botswana. Our findings can begin to inform public health strategies aimed at promoting improved health care, education, and social inclusion for this population in Botswana and other regions in Africa. (JAAD Int 2021;2:153-63.)

**Key words:** albinism; dermatology; discrimination; oculocutaneous albinism; persons or people living with albinism (PWA); skin cancer; skin cancer prevention; stigma.

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## INTRODUCTION

Oculocutaneous albinism (OCA) is a genetic condition characterized by hypopigmentation of the hair, skin, and eyes because of decreased melanin production by melanocytes. Although rare globally (1 in 20,000 births), OCA is more common across Africa with an estimated prevalence of 1 in 3900 in South Africa.<sup>1</sup> Because of the decreased melanin, which provides photoprotection by absorbing ultraviolet radiation, people living with albinism (PWA) have increased risks of visual defects and skin cancer, most commonly squamous cell carcinoma and basal cell carcinoma. Indeed, PWA in sub-Saharan Africa are at approximately 1000-fold greater risk of squamous cell carcinoma compared with the general population and often present with advanced neoplasms because of delayed diagnosis and treatment.<sup>2</sup> In addition to health challenges, prior literature indicated that PWA faced social and psychological challenges, particularly in Africa.<sup>3-10</sup> Differences in the physical appearances of PWA, along with associated myths and superstitions, can result in prejudices and misconceptions, leading to societal stigma, isolation, violent persecution, and ritual murders.<sup>6,9,10</sup>

Prior studies have characterized PWA in various regions of Africa including Tanzania, Uganda, Nigeria, and South Africa. However, the published data describing the sociodemographic characteristics and behaviors of PWA in Botswana was limited to a single case study of 2 teenagers, which identified poor educational experiences because of OCA-related physical limitations and negative attitudes from peers.<sup>11</sup> No studies have quantitatively examined PWA in Botswana or compared them against the population they live in. Because many challenges PWA face may be preventable, we sought to understand the demographics, health factors, sun protection behaviors, and psychosocial factors affecting PWA in Botswana and understand how these compared with those of the general population. We hypothesized that the social challenges PWA face in Botswana were similar to those that have been identified in other African regions such as poor skin health, stigma, and discrimination. Our goal was to identify the social determinants of health in

order to guide interventions for PWA in Botswana and other parts of Africa.

## METHODS

### Study design

We conducted a cross-sectional survey on a cohort of PWA and a reference group of patients without albinism (non-PWA). This was one arm of a pilot study that also included qualitative interviews of the same cohort of PWA (results were reported separately).<sup>12</sup>

### Setting

Botswana is a middle-income country with a near 90% literacy rate, a >70% urban population, and a high unemployment rate of 20%.<sup>13</sup> Although Botswana has a universal health care system, nearly half of the doctors in Botswana are based in two urban areas, leading to access

challenges, particularly for specialty care.<sup>14</sup> Botswana is heavily impacted by the HIV/acquired immunodeficiency syndrome epidemic with an adult prevalence rate of 20%, which strains the health care system.<sup>13,15</sup>

### Participants

From January 2018 to February 2019, a convenience sample of 50 PWA was obtained through recruitment from Princess Marina Hospital (PMH) Dermatology and Eye clinics, Dermatology Outreach Clinics (in Kanye, Mochudi, Mahalapye, and Lobatse), and at Tshimologo Albinism Association support group meetings. We included a non-PWA reference group to obtain a baseline for comparison of epidemiological characteristics, many of which had not been investigated in the local population. The non-PWA group was obtained from the pool of all patients who presented to the outpatient department at PMH on a given day via random sampling of assigned registration numbers. Nearly twice as many patients were enrolled in the non-PWA group in an effort to increase the statistical power of the analysis between groups. To obtain a diverse sample of outpatients who may be presenting with health problems similar to those of PWA (including skin, eye, and general health concerns), one-third of the 99 patients were recruited from each of the following clinics: dermatology (33), eye (33), and general ambulatory medicine (33). Patients aged <21 years

## CAPSULE SUMMARY

- People living with albinism (PWA) in Botswana experience unique economic, educational, health-related, and psychosocial challenges similar to those reported by PWA in other African countries.
- Besides skin and eye care, clinicians should be aware that PWA may need more psychosocial support than other patients. Dermatologists have opportunities to promote skin health and increase the social welfare of PWA.

*Abbreviations used:*

CI:	confidence interval
Non-PWA:	patients without albinism
OCA:	oculocutaneous albinism
OR:	odds ratio
PMH:	Princess Marina Hospital
PWA:	people living with albinism

or >75 years were excluded because they were considered vulnerable populations locally.

### Data collection

After consenting, participants completed a 70-questions survey, created by author VLW, to evaluate demographics, health status, health practices, health care access, self-perceptions, and beliefs/attitudes about albinism. The survey instrument was created based on clinical experience with PWA, input from PWA and other clinicians, and review of available literature on PWA in Africa. The instrument was reviewed by three local clinicians, four institutional review boards, and piloted with two PWA to obtain feedback for clarity and relevance of questions. The survey results were transcribed into the Research Electronic Database Capture (REDCap) tool (Vanderbilt University).

### Data analysis

The statistical analyses were performed using SAS/STATA 14.3, SAS 9.4 (SAS Institute). Descriptive statistics were used to describe, compare, and assess the magnitude of association between groups. For qualitative variables with >2 subcategories, we used chi-square tests. If the chi-square test was statistically significant, or if there was a large percentage difference in an end subcategory (>10%), we collapsed the subcategories into 2 categories and computed an odds ratio (OR) with 95% confidence intervals (CIs). For continuous level variables, we used t-tests to assess subgroup differences.

### Ethical considerations

Ethical approval was obtained from the institutional review boards of the University of Pennsylvania, the Botswana Ministry of Health and Wellness, the University of Botswana, and the PMH Ethics Committee.

## RESULTS

### Demographics

The demographics of the PWA and the non-PWA groups are described in [Table I](#). In the PWA cohort, the male-to-female ratio was 1:1.6 and 56% (28 of 50) identified as single. There were no statistically

significant differences between the PWA cohort and the non-PWA cohort in terms of age distribution, sex, ethnicity, and HIV status. Forty-six percent (23 of 50) of the PWA lived in a rural village compared with 25% (24 of 99) of the non-PWA. Differences in residence location were reflected in the distance from the capital, Gaborone: the PWA group had a nearly 3-fold increase in the odds of living <300 km away from Gaborone compared with the non-PWA group (95% CI, 1.19-6.92).

Eighteen percent (9 of 50) of the PWA reported obtaining a primary or lower level of education, compared with 10.1% of the non-PWA (10 of 99). A majority of both the PWA (78%) and the non-PWA (67.7%) reported completion of secondary education or achieving some university level of education. The proportion who received vocational training was higher in the non-PWA (22.2%, 22 of 99) than that in the PWA (4%, 2 of 50). In both groups, a majority of the respondents expressed a desire to attain more education than they received (72% of PWA and 76.8% of non-PWA).

Fifty-four percent (27 of 50) of PWA were unemployed and 20% (10 of 50) relied on government welfare as a source of financial support. Although the non-PWA also had a high level of unemployment (41%, 41 of 99), only 2% (2 of 99) utilized government welfare. Both the PWA and non-PWA relied mostly on themselves and family for financial support. Although 68.2% of the overall sample earned <5000 Pula (approximately 424 USD) a month, the PWA earned significantly less. The PWA had an over 4-fold increased odds of earning <1000 Pula (85 USD) per month (95% CI, 2.11-10.10).

### Health factors

The majority of patients in the PWA and non-PWA cohorts reported poor to average health (92% PWA and 96% non-PWA); however, the PWA had nearly a 3-fold increase in the odds of rating their access to health care as poor compared with the non-PWA group (OR, 2.72; 95% CI, 1.11-6.62). In terms of subspecialty care, the PWA reported higher rates of accessing dermatologic and ophthalmic care. Eighty-six percent (43 of 50) of the PWA had been examined by a dermatologist, compared with 29% (28 of 99) of the non-PWA group. A significantly higher proportion of the PWA group had their eyes examined compared with that of the non-PWA group (92% vs 77%, respectively). Although both groups had a similar distribution of visual defects requiring spectacles, the PWA were more likely to need glasses but be unable to obtain them (OR, 8.85; 95% CI, 3.83-20.4). There were significant differences in the participants' self-reported understanding of

**Table I.** Demographics of the surveyed PWA and the non-PWA reference group

Variable	PWA (N = 50)	Non-PWA reference group (N = 99)	X <sup>2</sup> -test (P value)	Odds ratios (95% CI)
	N (%)	N (%)		
Mean Age	37.9 (SD 14.8)	38.4 (SD 13.134)	-0.23 (.82)*	
Sex			0.19 (.66)	
Male	19 (38%)	34 (34%)		
Female	31 (62%)	65 (66%)		
Ethnicity			0.51 (.48)	
Motswana	50 (100%)	98 (99%)		
Religion			1.02 (.31)	
Christian	50 (100%)	97 (98%)		
Marital status			27.91 (<.0001)	
Single	28 (56%)	69 (71%)		
Married	9 (18%)	28 (29%)		
Divorced/Separated	2 (4%)	0 (0%)		
Cohabiting	11 (22%)	0 (0%)		
Number of children			3.62 (.16)	
None	19 (38%)	23 (23%)		2.03 (0.97-4.23)
1 to 3	25 (50%)	60 (61%)		
4 or more	6 (12%)	16 (16%)		
Children with albinism			0.44 (.51)	
Yes	1 (3%)	1 (1%)		
No	30 (97%)	75 (99%)		
Number of Siblings			6.66 (.04)	
None	0 (0%)	7 (7%)		
1 to 3	15 (30%)	40 (41%)		
4 or more	35 (70%)	50 (52%)		2.19 (1.06-4.52)
Relatives with albinism			52.75 (<.0001)	
Yes	31 (62%)	7 (7%)		21.44 (8.23-55.86)
No	19 (38%)	92 (93%)		
Residence location			6.98 (.03)	
Urban city center	14 (28%)	41 (42%)		
Semi-urban village <sup>†</sup>	13 (26%)	32 (33%)		
Rural village	23 (46%)	24 (25%)		2.59 (1.26-5.34)
Distance from capital			10.04 (.02)	
<20 km	15 (30%)	51 (55%)		
20-100 km	19 (38%)	27 (29%)		
100-300 km	2 (4%)	3 (3%)		
>300 km	14 (28%)	11 (12%)		2.86 (1.19-6.92)
Education			10.12 (.02)	
None to primary	9 (18%)	10 (10%)		2.31 (1.15-4.62)
Secondary	21 (42%)	29 (29%)		
University	18 (36%)	38 (38%)		
Other and vocation	2 (4%)	22 (22%)		
Desire to achieve higher education			0.40 (.52)	
Yes	36 (72%)	76 (77%)		
No	14 (28%)	23 (23%)		
Employment status			2.12 (.15)	
Employed	23 (46%)	58 (59%)		
Unemployed	27 (54%)	41 (41%)		
Sources of financial Support <sup>‡</sup>			NA	
Self	31 (62%)	63 (64%)		
Family	16 (32%)	24 (24%)		
Friends	2 (4%)	1 (1%)		
Community	1 (2%)	0 (0%)		
Government welfare	10 (20%)	2 (2%)		
Other	0 (0%)	3 (3%)		

Continued

**Table I.** Cont'd

Variable	PWA (N = 50)		Non-PWA reference group (N = 99)		X <sup>2</sup> -test (P value)	Odds ratios (95% CI)
	N (%)	N (%)	N (%)	N (%)		
Types of employment					NA	
Agriculture	1 (4%)		5 (9%)			
Business	0 (0%)		13 (22%)			
Education	3 (11%)		5 (9%)			
Service industry	5 (18%)		13 (22%)			
Tourism	1 (4%)		2 (3%)			
Self-Employed	8 (29%)		8 (14%)			
Health care	0 (0%)		7 (12%)			
Other	10 (36%)		5 (9%)			
Monthly income (in Pula)					18.51 (.0003)	
<1000	27 (61%)		21 (26%)			4.61 (2.11-10.10)
1000-5000	14 (32%)		34 (41%)			
5000-10000	1 (2%)		10 (12%)			
>10,000	2 (5%)		17 (21%)			

CI, Confidence interval; NA, not applicable; non-PWA, patients without albinism; PWA, people living with albinism.

\*t-test (P value).

<sup>†</sup>A semi-urban village can be considered as the outlying suburbs of an urban city center.

<sup>‡</sup>participants could choose multiple answers so percentage can be >100.

albinism, with 90% of PWA feeling that they had average to excellent understanding of the disease compared with 63.3% of non-PWA. However, in both groups, nearly one-quarter of the participants reported an incorrect underlying cause of albinism (26.5% PWA and 21.9% non-PWA). All health factors data are detailed in [Table II](#).

### Sun protection factors

[Table III](#) summarizes the sun protection factors employed by all respondents. There was no statistically significant difference in the overall daily sun exposure between the PWA and the non-PWA groups; however, the PWA displayed statistically significant differences in all other categories of sun protection behaviors. Importantly, 56% of the PWA spent >1 hour in the sun daily and 29% spent >4 hours. High proportions of PWA employed various sun-protective measures frequently-to-always, including applying sunscreen on the face (88%) and sun-exposed areas (88%) and wearing sun-protective clothing like hats (94%) and long-sleeved shirts (92%). Most PWA (82%) also reported avoiding peak sunlight hours frequently-to-always. In addition, 47% of the PWA reported seldom wearing sunglasses. In terms of knowledge about skin cancer, PWA strongly believed that skin cancer is preventable (94%), treatable (74%), and that sunscreen could prevent skin cancer (77%). Importantly, nearly all PWA (100%) and non-PWA (97%) believed that sunscreen should be freely provided for PWA.

### Psychosocial factors

Most PWA felt accepted by friends (88%) and family (94%). However, there was a significant difference between the PWA and the non-PWA groups in feelings of acceptance by their community. The PWA group had increased odds of not feeling accepted by their community compared with the non-PWA group (OR, 15.16; 95% CI, 5.25-31.81). A significantly higher proportion of PWA had experienced discrimination compared with that of the non-PWA group (54% vs 8.42%, respectively), and PWA had a 4-fold increase in the odds of being impacted by discrimination in their daily lives. The proportion that felt that PWA were stigmatized by society in Botswana was higher in the PWA than that in the non-PWA group (90% vs 48.98%, respectively), and the PWA had increased odds of being impacted by stigma in their social interactions (OR, 2.21; 95% CI, 1.08-4.54). Concerningly, 74% of the PWA reported witnessing mistreatment of PWA.

A majority of respondents from both groups believed that PWA deserved a chance for equal employment (94% PWA vs 88% non-PWA). However, a higher proportion of PWA believed that PWA deserved extra financial and social support compared with that of non-PWA (94% vs 77.78%, respectively) and that albinism should be considered a disability (50% vs 31.31%, respectively). Additional psychosocial data are summarized in [Table IV](#).

### DISCUSSION AND CONCLUSION

To our knowledge, this study is the first to quantitatively describe sociodemographic

**Table II.** Health factors of the surveyed PWA and the non-PWA reference group

Variable	PWA (N = 50)	Non-PWA reference group (N = 99)	X2-test (P value)	Odds ratio (95% CI)
	N (%)	N (%)		
Self-rated general health status			2.03 (.36)	
Poor	7 (14%)	9 (9%)		
Average	39 (78%)	86 (87%)		
Excellent	4 (8%)	4 (4%)		
Self-rated access to health care			6.53 (.04)	2.72 (1.11-6.62)
Poor	13 (26%)	11 (11%)		
Average	30 (60%)	76 (79%)		
Excellent	7 (14%)	9 (9%)		
HIV status			0.004 (.95)	
Positive	10 (20%)	20 (20%)		
Negative	39 (78%)	76 (77%)		
Unknown	1 (2%)	3 (3%)		
Number of visits to a physician in the past year				
None	6 (12%)	16 (16%)	0.92 (.63)	
1 to 3	27 (54%)	45 (46%)		
4 or more	17 (34%)	36 (37%)		
Has visited a traditional healer			0.21 (.65)	
Yes	3 (6%)	8 (8%)		
No	47 (94%)	91 (92%)		
Has been examined by a dermatologist			43.75 (<.0001)	
Yes	43 (86%)	28 (29%)		15.36 (6.1-38.2)
No	7 (14%)	70 (71%)		
Frequency of visits to a dermatologist			3.68 (.16)	
Once	7 (16%)	7 (26%)		
Every 1-2 years	2 (5%)	4 (15%)		
Every 3-9 months	34 (79%)	16 (59%)		
Has had eyes examined			5.20 (.02)	3.48 (1.13-10.7)
Yes	46 (92%)	76 (77%)		
No	4 (8%)	23 (23%)		
Frequency of eye examinations			1.36 (.51)	
Once	22 (49%)	28 (39%)		
Every 1-2 years	18 (40%)	32 (44%)		
A few times a year	5 (11%)	12 (17%)		
Has a visual defect that requires refractive lenses			1.62 (.20)	
Yes	29 (58%)	46 (47%)		1.56 (0.78-3.10)
No	21 (42%)	52 (53%)		
Unable to acquire needed spectacles			29.61 (<.0001)	
Yes	34 (68%)	22 (26%)		
No	11 (22%)	63 (74%)		8.85 (3.83-20.4)
Able to access free spectacles			6.77 (.009)	
Yes	8 (28%)	4 (7%)		
No	21 (72%)	53 (93%)		
Self-rated level of understanding of albinism			23.04 (<.0001)	
Poor	5 (10%)	36 (37%)		
Average	33 (66%)	59 (60%)		
Excellent	12 (24%)	3 (3%)		
Beliefs on the cause of albinism			5.08 (.08)	
Genetic disorder	36 (73%)	75 (78%)		

Continued

**Table II.** Cont'd

Variable	PWA (N = 50)	Non-PWA reference group (N = 99)	X2-test (P value)	Odds ratio (95% CI)
	N (%)	N (%)		
Transmittable medical disease	6 (12%)	17 (18%)		
Other	7 (14%)	4 (4%)		

CI, Confidence interval; non-PWA, patients without albinism; PWA, people living with albinism.

**Table III.** Sun protection factors of the surveyed PWA and the non-PWA reference group

Variables	PWA (N = 50)	Non-PWA reference group (N = 99)	X2-test (P value)	Odds ratio (95% CI)
	N (%)	N (%)		
Hours in the sun daily			4.85 (.09)	
<1 hr	22 (45%)	23 (26%)		2.27 (1.08-4.74)
1-3 hr	13 (27%)	32 (37%)		
4 or more hr	14 (29%)	32 (37%)		
Sunscreen used on face*			72.49 (<.0001)	
Seldom	6 (12%)	77 (81%)		
Frequently	11 (22%)	12 (13%)		
Always	33 (66%)	39 (27%)		
Sunscreen used on all sun-exposed areas*			80.51 (<.0001)	
Seldom	6 (13%)	85 (88%)		
Frequently	9 (19%)	6 (6%)		
Always	33 (69%)	6 (6%)		
Wears a hat*			59.65 (<.0001)	
Seldom	3 (6%)	51 (52%)		
Frequently	7 (14%)	32 (33%)		
Always	39 (80%)	15 (15%)		
Avoids peak sunlight hours* (10 am - 2pm)			16.41 (.0003)	
Seldom	9 (18%)	44 (47%)		
Frequently	18 (37%)	33 (35%)		
Always	22 (45%)	16 (17%)		
Wears sunglasses*			7.01 (.03)	
Seldom	23 (47%)	62 (66%)		
Frequently	9 (18%)	17 (18%)		
Always	17 (35%)	15 (16%)		
Utilizes shade devices*			9.72 (.008)	
Seldom	17 (34%)	55 (57%)		
Frequently	15 (30%)	27 (28%)		
Always	18 (36%)	15 (15%)		
Wears long sleeves*			36.15 (<.0001)	
Seldom	4 (8%)	51 (54%)		
Frequently	25 (50%)	35 (37%)		
Always	21 (42%)	9 (9%)		
Wears long pants*			6.65 (.04)	
Seldom	4 (8%)	19 (20%)		
Frequently	16 (33%)	39 (41%)		
Always	29 (59%)	36 (38%)		
Frequency of daily sunscreen application			75.70 (<.0001)	
Never	3 (6%)	72 (75%)		
Once a day	13 (27%)	18 (19%)		
2+ more a day	33 (67%)	6 (6%)		30.94 (11.16-85.75)

Continued

**Table III.** Cont'd

Variables	PWA (N = 50)	Non-PWA reference group (N = 99)	X2-test (P value)	Odds ratio (95% CI)
	N (%)	N (%)		
Believes it is possible to prevent yourself from getting skin cancer			4.16 (.04)	
Yes	47 (94%)	80 (82%)		3.53 (1.0 -12.6)
No	3 (6%)	18 (18%)		
Believes skin cancer is treatable			1.10 (.29)	
Yes	37 (74%)	79 (81%)		
No	13 (26%)	18 (19%)		
Believes sunscreen can prevent skin cancer			1.45 (.23)	
Yes	37 (77%)	64 (67%)		
No	11 (23%)	31 (33%)		
Believes PWA should be provided free sunscreen			1.55 (.21)	
Yes	50 (100%)	96 (97%)		
No	0 (0%)	3 (3%)		

CI, Confidence interval; non-PWA, patients without albinism; PWA, people living with albinism.

\*Scale: Seldom = performs task never to a few times a year; Frequently = performs task from a few days a week to a few times a month; Always = performs task every day.

characteristics of a cohort of PWA in Botswana. It indicated that unique economic, educational, health-related, and psychosocial challenges are faced by PWA compared with people without albinism in the population.

Compared with prior studies of PWA in Africa, our cohort had a higher mean age (38 years).<sup>7,8,16,17</sup> However, this may be because of location-specific demographics, as the non-PWA cohort had a similar mean age. The PWA surveyed reported living in more rural locations, having a lower income, and depending more on government welfare compared with the non-PWA group. Such factors may reduce health care access and limit the ability to purchase sun-protective measures. Although Botswana has a universal health care system and 95% of the population lives within 8 km of a health care facility, most providers and all tertiary level care facilities are in urban areas.<sup>14</sup> Physicians with specialty knowledge in dermatology and ophthalmology, which are vital areas of care for PWA, were limited in the areas where most PWA lived.

Significantly higher proportions of PWA rated their access to health care as poor and were unable to acquire corrective spectacles despite a similar rate of visual defects compared with non-PWA. Poor health care access had been cited as a common challenge for PWA in Africa, which could contribute to the development of preventable complications of skin cancers and visual impairments.<sup>1,2,16,18</sup> Uncorrected visual impairments can then hinder

education, resulting in reduced opportunities for meaningful employment.<sup>8,18</sup> These findings were further supported by an additional arm of this study, which analyzed 27 interviews from members of this PWA cohort and demonstrated that limited skin/eye care access, visual impairment, and an unsupportive educational environment were major contributors to poor quality of life.<sup>12</sup> There was a clear disconnect between participants self-perceived versus actual understanding of the condition of albinism in both cohorts, demonstrating the need for increased efforts to improve overall albinism education and awareness in Botswana.

The PWA in our cohort had high rates of use of sun-protective measures, with the exception of sunglasses. Compared with PWA in other African regions, our study population had a much higher adoption of sun-protective behavior. However, ultraviolet damage was still a concern, given that nearly a third spent >4 hours daily in the sun and nearly 30% failed to always wear sunscreen. A recent study of PWA in the Democratic Republic of the Congo found that a majority of respondents had never used sunscreen, spent at least 4 hours in the sun daily, and only a minority used fully sun-protective clothing.<sup>16</sup> Similarly, a study done in Tanzania found that 50% of the PWA surveyed spent >6 hours daily in the sun, 62% did not wear a hat, and 80% did not use fully sun-protective clothing.<sup>7,19</sup> The increased rates of sun-protective behavior in our study population are likely the results of a dedicated



**Table IV.** Psychosocial factors of the surveyed PWA and the non-PWA reference group

Variable	PWA (N = 50)	Non-PWA reference group (N = 99)	X2-test (P value)	Odds ratio (95% CI)
	N (%)	N (%)		
Feels accepted by family			3.12 (.08)	
Yes	47 (94%)	97 (99%)		
No	3 (6%)	1 (1%)		
Feels accepted by peers			2.29 (.13)	
Yes	44 (88%)	93 (94%)		
No	6 (12%)	5 (5%)		
Feels accepted by community			34.50 (<.0001)	
Yes	27 (55%)	93 (95%)		
No	22 (45%)	5 (5%)		15.16 (5.25-31.81)
Frequency of facing discrimination*			37.19 (<.0001)	
Seldom	23 (46%)	87 (92%)		
Frequently	23 (46%)	7 (7%)		12.77 (5.12-31.81)
Always	4 (8%)	1 (1%)		
Amount of impact discrimination has on daily life				
No impact	9 (18%)	45 (50%)	16.93 (.0002)	
Little to some impact	22 (44%)	32 (36%)		4.56 (1.98-10.46)
Moderate to major impact	19 (38%)	13 (14%)		
Amount of impact stigma has on social interactions				
No impact	17 (34%)	48 (53%)	6.42 (.04)	
Little to some impact	20 (40%)	31 (34%)		2.21 (1.08-4.54)
Moderate to major impact	13 (26%)	11 (12%)		
Believes PWA are stigmatized by society in Botswana			23.86 (<.001)	
Yes	45 (90%)	48 (49%)		9.37 (3.43-35.62)
No	5 (10%)	50 (51%)		
Has witnessed mistreatment of PWA			18.98 (<.0001)	
Yes	37 (74%)	35 (36%)		5.04 (2.37-10.73)
No	13 (26%)	62 (64%)		
Believes PWA deserve equal employment opportunities			1.37 (.24)	
Yes	47 (94%)	87 (88%)		
No	3 (6%)	12 (12%)		
Believes PWA are disabled			4.95 (.03)	
Yes	25 (50%)	31 (31%)		2.19 (1.09-4.41)
No	25 (50%)	68 (68%)		
Believes PWA deserve extra financial and social service support			6.26 (.01)	
Yes	47 (94%)	77 (78%)		4.48 (1.27-15.77)
No	3 (6%)	22 (22%)		

CI, Confidence interval; non-PWA, patients without albinism; PWA, people living with albinism.

\*Scale: Seldom = performs task never to a few times a year; Frequently = performs task from a few days a week to a few times a month; Always = performs task every day.

albinism care program at the PMH dermatology clinic, established 1 year prior to this study. In addition to providing health care, the program increases awareness of specific health issues of

PWA and educates patients about sun-protective behaviors.<sup>20</sup> Similar interventions are making headway in other parts of Africa to increase knowledge of albinism and the importance of sun protection for

skin cancer prevention. Comprehensive albinism care programs that are supported by local health care systems such as Standing Voice's in East Africa serve as a model to create sustainable improvements in the health and quality of life for PWA across Africa.<sup>21-27</sup>

Many PWA in Botswana were impacted by discrimination, and few reported feeling accepted by their community. The literature on beliefs surrounding albinism in Africa demonstrated the stigmatization and "othering" of PWA that has been common across various regions of Africa.<sup>3-11</sup> This typically led to the societal and self-imposed marginalization of this population, subsequently having a negative impact on education, professional advancement, and psychosocial health.<sup>4</sup> Through interviews detailed in a separate manuscript,<sup>12</sup> our cohort of PWA also emphasized that stigma and discrimination had a far-reaching impact across physical, psychosocial, and environmental health factors throughout their lives. In addition to psychosocial trauma from stigma/discrimination, PWA in some parts of Africa also face acts of violence and ritual murders committed because of superstitious and traditional beliefs surrounding the body parts of PWA.<sup>6,9,10</sup> The United Nations has recognized these injustices as an urgent human rights crisis,<sup>28</sup> and Botswana is, at the time of publication, one of 11 countries in Africa that has not ratified the United Nations Convention on the Rights of Persons with Disabilities in order to protect the human rights of citizens with OCA.<sup>29</sup>

Our study was limited by the use of a non-validated survey tool, a small sample size, convenience sampling, selection bias because of recruitment sites focused on urban health centers/support groups, and an inability to specifically match PWA cases with the control cohort. Response bias and participation bias could additionally limit the ability to generalize our findings to the entire Botswana population or to other populations of PWA. However, this pilot study provided a critical baseline of epidemiological characteristics for PWA in Botswana that will inform future studies. Analysis of larger, more regionally distributed cohorts with validated survey tools and long-term follow up are needed to better understand the unique circumstances facing PWA in Botswana and how these affect health outcomes.

This study highlighted the challenges PWA can face in comparison with non-PWA. Though Botswana has a relatively good health care infrastructure and strong economy, the PWA surveyed experienced both medical and psychosocial challenges. We highlighted the need for public health interventions to support PWA in Botswana, including

increased access to specialty care, equitable education and employment opportunities, and campaigns to increase awareness and destigmatize OCA within society. Our findings can begin to inform public health strategies aimed at promoting improved health care, education, and social inclusion for this population in Botswana and other regions in Africa.

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### Conflict of interest

Dr Williams is currently employed by Merck & Co, Inc, but the current study was conducted prior to this relationship.

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