ORIGINAL ARTICLE

Quality of life in people living with albinism in a tertiary Hospital in Southern Nigeria

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Abstract

Background: Nigeria has the highest prevalence of albinism in the world. However there is still lack of understanding of the cause of albinism. This has led to superstitious beliefs that limit social acceptance and integration of people living with albinism into the communities with consequent negative social and psychological effects. This study assessed the quality of life (QoL) and associated factors in people with albinism living in Benin City, Nigeria

Methodology: This was a cross-sectional study conducted in Benin City that assessed QoL of people living with albinism using the Dermatology Life quality Index (DLQI) questionnaire. The DLQI scores is inversely related to QoL. Mann-Whitney U was used to compare median DLQI scores across groups and p value <0.05 was taken as significant.

Results: Seventy-three people with albinism participated in the study with a mean age of 24±11 years. Fifty-eight(79.5%) were adults, 16(21.9%) had photodermatoses, 15(20.5%) used sunscreens and 13(17.8%) used protective clothing. Those with photodermatoses had higher median DLQI scores; 9(9) vs 3.5(8), p = 0.016. The median DLQI scores was also higher in those who did not use sunscreens; 9(8.5) vs 3(5), p = <0.001. There was no significant difference in median DLQI scores across gender, age group, level of education and income earned

Conclusion: People living with albinism in Benin City have reduced QoL. The use of sunscreens and the absence of photodermatoses were associated with better QoL.

Keywords: Quality of life, albinos, sunscreens

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Introduction

Albinism is a congenital disorder characterized by the complete or partial absence of pigment in the skin, hair and eyes due to absence or defect of tyrosinase, a copper-containing enzyme involved in the production of melanin[1].In Africa, where albinism is more prevalent and better studied, there is increasing evidence of social discrimination and stigmatization of these persons[2]. It is thus, a hereditary disorder that affects the individual and his family from a medical, social and psychological point of view[2]. These individuals are subjected to prejudice and discrimination from the community causing them to be more unstable emotionally and develop a less assertive personality than people without albinism[2]. Therefore, the quality of life of albinos is compromised, which may become evident in the child's performance and relationships at school, followed by difficulty in finding a job and a spouse, when compared to the rest of the population.[3] Nevertheless, people with albinism have normal longevity, fertility and development.[4]

People with albinism are faced with enormous challenges under ultraviolet light exposure. Their quality of life is severely affected and worsened by the lack of community awareness, cultural beliefs and superstitions within the society[5]. Poor performance in their formal education and a discriminating work environment results in an economically disadvantaged group of individuals that is engulfed in a vicious cycle of isolation and poverty.[5]

Some studies have been done on albinism in Africa. However, studies on quality of life (QoL) in people living with albinism are few especially in West Africa. In Nigeria, the aetiological beliefs about albinism continue to be heavily influenced by culture and superstition rather than genetics. This study determined the QoL and associated factors amongst albinos in Benin City. The findings of this study will provide information on QoL in people living with albinism. This will be useful for government and health workers to adopt strategies of improving the QoL in people with albinism.

Methodology

This is a cross-sectional study that was carried out between June 2014 and June 2015 in the Dermatology Unit through an albino outreach clinic at the University of Benin Teaching Hospital. The hospital is located in the South-South geopolitical region in Nigeria, Benin City, Edo State. It is one of the 4 public tertiary health care institutions in Edo State and has 800 bed capacity. It receives referrals from within Edo State and neighboring states like Delta, Ondo, Anambra, Ekiti, Kogi, and Bayelsa. The Dermatological Unit is one of the subspeciality arms of the Department of Medicine. It is supervised by three consultant dermatologists and seven residents doctors.

Study Population

Consenting people living with albinism who were 4 years and above presenting at the Dermatology Outreach Albino Clinics in the University of Teaching Hospital, Benin City.

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Sample Size Determination

Using the fisher's formula [6],

$$N = \frac{z^2 pq}{d^2}$$

n = minimum sample size

Z = Normal standard deviation 99% confidence level of 2.58

P = prevalence

q = 1-p

d = margin of error = 0.01

Studies describe a prevalence of 1 in 1000 (0.1%) [7]

$$\text{Therefore } n = \frac{2.58^2 \times 0.001 \times 0.999}{0.01^2} = 66.4$$

Attrition rate of 10%= 6.6

Hence sample size = 73

Study Group - 73

A sample size of 73 was utilized for the study population.

Ethical Consideration

Ethical clearance was obtained from the hospital for the study. Informed consent was obtained directly from the adult study participants and from the parents or guardian of participants who were children. In addition, information received was treated with utmost confidentiality.

Sampling Technique

An albino outreach clinic was set up in the Dermatology Unit of the University of Benin Teaching Hospital (UBTH), Benin city. A snowball sampling technique was utilized where any client with albinism presenting at the clinic and who consented to study was encouraged to nominate another albino. The nominated subjects were included and this continued until the total number of clients were obtained.[8]

Data Management

An interviewer administered questionnaire was used to extract information from each respondent. The questionnaire included information on socio-demographics such as age, sex, marital status, educational status, employment status and monthly income. Information on the use of sunscreens and protective clothing was also included in the questionnaire. All study participants were examined for photodermatoses and dermoscopy was used to boost diagnostic accuracy where necessary.

The dermatological life quality was assessed using validated life quality index questionnaires Adult Dermatology Life Quality Index Questionnaire was used for participant who were 16 years and above while Children Dermatology Life Quality Index questionnaire was used for those between 4 and 15 years .[9-11]

This questionnaire has 10 questions and each question is scored 0 to 3 based on the response: not relevant or not at all is scored 0, a little is scored '1', a lot is scored '2' and very much is scored '3' The DLQI is calculated by summing the score of each question resulting in a maximum of 30 and a minimum of 0. The DLQI scores is inversely related WHO QoL scores.

Interpretation of DLQI Scores

0 – 1: no effect at all on patient's life
2 – 5: small effect on patient's life
6 – 10: moderate effect on patient's life
11 – 20: very large effect on patient's life
21 – 30: extremely large effect on patient's life

Data Analysis

All data generated were analysed using statistical package for social sciences (SPSS) version 21.0. Results were presented in tabular form. Discrete variables were presented as frequency and percentages. Continuous variable was presented as mean and standard deviation while skewed data was presented as median and interquartile range. Mann-Whitney U and Kruskal Wallis test were used to compare median DLQI scores across groups. $P < 0.05$ was taken as statistically significant.

Results

A total of 73 albinos participated in the study. There were 41 females and 32 males. The mean age for the albino population was 24±11 years.

Table 1: Socio-Demographic Data of Study Population

Parameter	Albino N = 73 n(%)
Age	
Mean±SD	24.1 ± 11.3 years
<16 years	15(20.5)
≥16 years	58(79.5)
Sex	
Female	41(56.2)
Male	32(43.8)
Employment Status	
Employed	16(21.9)
Self-Employed	12(16.4)
Unemployed	24(32.9)
Not Eligible	21(28.8)
Marital Status	
Married	9(12.3)
Separated	1(1.4)
Single	47(63.0)
Not Eligible	17(23.3)
Educational Status	
None	13(17.8)
Primary	3(4.1)
Secondary	12(16.4)
Tertiary	45(61.6)
Monthly Income (N)	
<20,000	48(65.8)
20,000 to 49,000	10(13.7)
≥50,000 to 99,000	15(20.5)
Ethnicity	
Bini	17(23.3)
Esan	35(47.9)
Igbo	16(21.9)
Others	5(6.8)

Fifty-eight (70.5%) were 16 years and above, 46(63%) were single, 9(2.3%) were married and 1(1.4%) was separated. Sixteen(21.9%) were employed, 45(61.6%) had tertiary education and 15(20.5%) earned ₦50,000 and above. Esan, Bini and Igbo ethnic groups were the most frequently observed ethnic groups with a frequency of 47.9%, 23.3% and 21.9%, respectively. (Table 1)

Table 2: Comparison of Median DLQI scores across various groups

	n	Median(IQR)	P value
Gender			
Male	32	9(10.25)	0.058
Female	41	6(8)	
Age Group			
< 16 years	15	8(9)	0.858
≥ 16 years	58	7(9)	
Level of Education			
None and Primary	16	8.5(9.75)	0.986
Post-primary	57	7(8.5)	
Income*			
<N 20,000	48	7.5(9.75)	0.447
N 20,000-49,000	10	7.5(5.25)	
N 50,000-99,000	9	9(8)	
>N 99,000	6	1.5(5.25)	
Presence of Photodermatoses			
Yes	16	9(9)	0.016
No	57	3.5(8)	
Use of Sunscreens			
Yes	15	3(5)	<0.001
No	58	9(8.5)	
Use of Protective Clothing			
Yes	13	7(8)	0.767
No	60	7(9.75)	

*Kruskal Wallis Test used

Sixteen (21.9%) had photodermatoses, 15(20.5%) used sunscreens and 13(17.8%) used protective clothing. The median (IQR) dermatology life quality index (DLQI) score of the children was 8(9) while that of the adult population was 7(9). There was no statistical difference ($p = 0.858$). The females had lower median DLQI scores compared to males; 6(8) vs 9(10.25) $p = 0.058$.Those with photodermatoses had higher median DLQI scores; 9(9) vs 3.5(8), $p = 0.016$. The median DLQI scores was also higher in those who did not used sunscreens; 9(8.5) vs 3(5), $p = < 0.001$. There was no significant difference in median DLQI scores across level of education and income earned.

Discussion

The median DLQI scores of both children and adults living with albinism showed that they have reduced QoL.This is similar to study by Samson et al[1] who reported a poor QoL in albino population. Social discrimination and superstitious beliefs have largely contributed to this reduced quality of life. In addition, the effect of the sun on their melanin deficient skin leads to sun induced damage of this aesthetic organ. Furthermore, social discrimination resulting from poor awareness about albinism and superstitious belief system regarding the condition may contribute the impaired QoL they experience.[7] Like other people with disability, people with albinism face discrimination and segregation and are often avoided by their families and communities.[7]African albinos endure segregation and threat throughout their lives and are thus forced to struggle to make ends meet as they are deprived of same opportunities as their non-albino peers who are not subjected to the same cultural and psychological challenges.

The study participants who used sunscreens and those without photodermatoses had a better DLQI scores compared to others. Surprisingly, less than 25% of the people living with albinism in this study used sunscreen and protective clothing which have been reported to have protective effect on their skin against the damaging effect of the ultraviolet light Regular use of sunscreens has been reported to reduce actinic keratoses, solar elastosis, skin malignancies such as squamous cell carcinoma and melanoma.[12] While there is limited understanding of the mechanisms of adverse health effects induced by UV light exposure, it is well known that photo-ageing, photocarcinogenesis and photo-immunosuppression are sequelae of UV exposure, particularly the UVA range (320–400 nm).[13] Therefore, photo-induced or photo-aggravated dermatoses may be prevented with the use of sunscreen with improvement in quality of life of albinos.

People with albinism in Nigeria represent one of the largest vulnerable groups in the country prone to a poor sense of well-being and self-satisfaction.[7] This may have negative consequent effect on their quality of life. The poverty and lack of education they suffer did not stem from mental or physical disability, but mostly as a result of social discrimination, social exclusion and in some cases human right abuse because of their skin colour.[1]

Limitation of study

The finding of this study cannot be generalized because it is a single centre study with a relatively small sample size, however the strength of this study lies in the fact that it is the first study to assess the QoL in people living with albinism in Southern Nigeria

Conclusion

This study has shown that QoL in people living with albinism is reduced. The use of sunscreens and the absence of photodermatoses are associated with better quality of life in them. We recommend that regular health education should be given to people living with albinism on the use of sunscreens and protective clothing which may improve their QoL.

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