



## Quality of Life and Photodermatoses in People with Albinism in Ogun State, Nigeria

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## Abstract

This study investigated the quality of life and prevalence of photodermatoses in individuals with albinism in Ogun State, Nigeria. The study adopted a cross-sectional design with data collected from 73 respondents with albinism. The majority of respondents were below 40 years old (72.6%), single (69.86%), had primary education (49.32%), and identified as Muslim (46.58%). Almost all respondents had oculocutaneous albinism (OCA) (95.89%). The overall quality of life was reported as poor (43.84%) or very poor (26.03%) by most respondents. Satisfaction with physical health and financial situation was notably low, whereas contentment with mental health was higher. However, respondents reported that albinism significantly affected their ability to work or study, personal relationships, and emotional well-being. Almost all respondents (97.26%) had experienced photodermatoses, with multiple types of sun-induced skin disorders reported. The most common photodermatoses included photoallergic eruption (22.77%), polymorphous light eruption (20.46%), and actinic keratosis (19.47%). Over 45% of respondents experienced skin problems related to sunlight exposure more than five times in the past year. The severity of skin problems was rated as severe (31.51%) or moderate (26.03%) by most respondents. Sun-protective clothing (38.64%) and limiting time outdoors (35.80%) were the most common protective measures employed. All respondents had received support, primarily from non-governmental organizations (41.95%), followed by government aid (24.14%). Nevertheless, satisfaction with the received support was low. Access to healthcare was reported as poor (27.40%) or very poor (23.29%) by a significant proportion of respondents. A substantial majority of respondents (95.89%) had experienced discrimination or stigma due to their condition. Age, marital status, and education level significantly affected the quality of life of people with albinism, while the type of albinism and religion did not. People who had experienced photodermatoses reported a significantly worse quality of life. The study concludes that individuals with albinism in Ogun State, Nigeria, face significant challenges related to their physical health, quality of life, and societal acceptance. Further supportive interventions and educational programs are needed to address these issues.

**Keywords:** Albinism; Photodermatoses; Quality of Life

## Introduction

Albinism is a genetic condition that affects approximately 1 in 20,000 people worldwide [1]. It is characterized by a lack or complete absence of pigment in the skin, hair, and eyes. This condition brings with it an increased susceptibility to the sun and bright light, leading to various skin disorders known as photodermatoses [2]. This background study aims to investigate the impact of photodermatoses on the quality of life (QoL) of people with albinism living in Ogun, Nigeria.

Albinism is particularly common in Africa, with a prevalence as high as 1 in 1,000 to 1 in 5,000 in some regions [3]. The burden of the disease is more pronounced in the sub-Saharan region, where Nigeria is located, due to the intense solar radiation, limited health care resources, and social stigma associated with the condition [4].

Photodermatoses represent a group of conditions triggered by an abnormal reaction to sunlight. These disorders are characterized by a variety of symptoms, such as itching, redness, scaling, and

hyperpigmentation, and they can significantly impair a person's QoL [5]. Photodermatoses are particularly concerning for people with albinism, who lack the natural skin protection from the sun's harmful ultraviolet (UV) radiation [6].

The QoL of people with albinism can be affected on multiple levels. Firstly, there is the physical burden of photodermatoses, which may result in discomfort and, in severe cases, life-threatening skin cancers [6]. Secondly, there is a psychological impact. People with albinism often face social stigmatization and discrimination due to their appearance, leading to mental health issues such as depression and anxiety [7]. Thirdly, there is the economic impact. The cost of managing photodermatoses can be high, and the condition may affect a person's ability to work or attend school, leading to further economic hardship [8].

Despite the importance of understanding the impact of photodermatoses on the QoL of people with albinism in Nigeria, there has been a paucity of research in this area. Most studies have

focused on the epidemiology of albinism and the genetic basis of the condition [9]. The few studies that have explored QoL have mainly focused on mental health issues [7], leaving a significant gap in understanding the holistic impact of photodermatoses on the QoL of people with albinism. Therefore, this research aims to fill this gap by exploring the QoL and photodermatoses in people with albinism in Ogun State, Nigeria.

## Research Methodology

### Research design

This research is a cross-sectional descriptive study designed to investigate the quality of life and photodermatoses in people with albinism in Ogun State, Nigeria.

### Study population

The population of the study was members of the albino foundation in Ogun State, a non-governmental organization committed to addressing the plight of people with albinism who were of different ages, and sex.

### Sample size determination

Sample size was calculated using the Fisher's formula as stated in Roli and Abel [10].

$$n = \frac{Z^2 (Pq)}{e^2}$$

where n = minimum sample size

Z = 2.58 at 99% confidence level,

P = known prevalence of photodermatoses in people with albinism

e = error margin tolerated at 1% = 0.01

q = 1 - p

According to previous research [10], the prevalence of photodermatoses in people with albinism in southern Nigeria is 1 in 1000 people making 0.1%

P = 0.1% = 0.001

q = 1 - p

= 1 - 0.001

= 0.999

e = error margin tolerated at 5% = 0.05

e<sup>2</sup> = 0.0025

$$n = \frac{(2.58)^2 (0.001 \times 0.999)}{(0.01)^2}$$

n = 66.5

The minimum sample size was 67 and was adjusted to 73 to account for non-response rate of 10%.

### Data collection instrument

The research tool was a self-administered questionnaire, formulated in English. The questionnaire consisted of four sections: demographics, quality of life, photodermatoses, as well as support and access to healthcare. The questionnaire was structured based on previously validated questionnaires for similar studies [11,12]. The instrument was duly validated with the help of experts in the field of health social work while the reliability was ensured through the use of Cronbachs' alpha which yielded reliability coefficient r = 0.86; r = 0.78 and r = 0.84 respectively. Top of Form

### Data analysis

Data collected was coded and entered into the Statistical Package for the Social Sciences (SPSS) version 26 for analysis. Descriptive statistics (frequencies and percentages) were used to summarize the data. Chi-square tests were conducted to determine the association between categorical variables. A significance level of 0.05 was used for all statistical tests.

### Ethical consideration

The research was conducted in accordance with ethical principles, including informed consent, confidentiality, and data protection. Participants were informed of the purpose of the research and had the option to withdraw at any time without any consequences.

### Limitations of study

The study is limited by the sample size, which may not be representative of the entire population. The study is also limited by the self-reporting nature of the questionnaire, which may be subject to social desirability bias.

**Results**

From the analysis of data, the age group below 20 forms the highest proportion at 35.61%. A majority of the respondents (69.86%) were single. In terms of education, most have received primary education (49.32%). There’s an almost even split between Islamic (46.58%) and Christian (45.21%) respondents. Regarding types of albinism, 95.89% of respondents have Oculocutaneous albinism (OCA) (Table 1). Most of the respondents are dissatisfied with their physical health (69.86%) and financial situation (71.23%). About 46.58% strongly agree that their condition affects their ability to work or study, and 57.53% agree that they often experience negative feelings like sadness, desperation, anxiety, and depression (Table 2).

The majority of respondents rate their overall quality of life as poor (43.84%) or very poor (26.03%) (Figure 1). Almost all respondents (97.26%) have experienced photodermatoses (Table 3). Among these, the most common types are photoallergic eruption (22.77%), polymorphous light eruption (20.46%), and actinic keratosis (19.47%). Most respondents have experienced sunlight-related skin problems more than five times in the last year (45.21%) (Table 3). All the respondents had received some form of support, with the majority receiving aid from Non-Governmental Organizations (NGOs) (41.95%) (Table 4). However, most respondents are unsatisfied (38.36%) or very unsatisfied (24.66%) with the support they receive. Almost all respondents (95.89%) have experienced discrimination or stigma due to their condition. Most of them believe their healthcare providers are well knowledgeable (47.95%) about albinism and related skin conditions.

The results in Table 5 shows different demographic factors affect the quality of life of albinos. It showed that age, marital status, and level of education have a significant impact on the overall quality of life (P-value < 0.05). There’s a notable difference in the quality of life between the single and married respondents, with the latter showing better ratings. Those with tertiary education seem to have a better quality of life compared to others. Those who have not experienced photodermatoses seem to have a better quality of life (Table 6). (Table 1,2, Figure 1, Table 3-7)

Demographic Information	Frequency	Percentage (%)
Age (in years)		
Below 20	26	35.61
20-29	13	17.81
30-39	14	19.18
40 – 49	11	15.07
50 – 59	6	8.22
60 and above	3	4.11
Marital Status		
Single	51	69.86
Married	20	27.40
Separated/Divorced/ Widowed	2	2.74
Level of Education		
No formal education	4	5.48
Primary	36	49.32
Secondary	19	26.03
Tertiary	14	19.18
Religion		
Islam	34	46.58
Christianity	33	45.21
Others	6	8.22
What type of albinism do you have? (If known)		
Oculocutaneous albi- nism (OCA)	70	95.89
X-linked ocular albi- nism (XLOA)	1	1.37
Hermansky-Pudlak Syndrome (HPS)	0	0.00
Chediak-Higashi Syn- drome	0	0.00
Others	0	0.00
I don't know	2	2.74

**Table 1:** Demographic Distribution of Respondents.

Quality of Life	Responses				
	Strongly Agree (%)	Agree (%)	Neutral (%)	Disagree (%)	Strongly Disagree (%)
I am satisfied with my physical health	2 (2.74)	8 (10.96)	6 (8.23)	51 (69.86)	6 (8.23)
I am content with my mental health	21 (28.77)	33 (45.21)	00 (0.00)	10 (13.70)	9 (12.33)
I am capable of managing my daily routine	15 (20.55)	16 (21.92)	11 (15.07)	22 (30.14)	9 (12.33)
I have good relationships with my friends and family	19 (26.03)	31 (42.47)	4 (5.48)	13 (17.81)	4 (5.48)
I am able to participate in social activities and events	5 (6.85)	12 (16.44)	14 (19.18)	36 (49.32)	6 (8.23)
I feel accepted in my community	4 (5.48)	9 (12.33)	6 (8.22)	41 (56.16)	13 (17.81)
I am comfortable with my financial situation	2 (2.74)	5 (6.85)	1 (1.37)	52 (71.23)	13 (17.81)
My condition affects my ability to work or study	34 (46.58)	28 (38.36)	5 (6.85)	3 (4.11)	3 (4.11)
My condition affects my personal relationships	26 (35.62)	28 (38.36)	00 (0.00)	10 (13.70)	9 (12.33)
My condition impacts my emotional well-being	15 (20.55)	39 (53.43)	2 (2.74)	9 (12.33)	8 (10.96)
I often have negative feelings like sadness, desperation, anxiety, depression	21 (28.77)	42 (57.53)	3 (4.11)	4 (5.48)	2 (2.74)
I feel happy with my overall quality of life	6 (8.22)	5 (6.85)	11 (15.07)	32 (43.84)	19 (26.03)

Table 2: Quality of Life.

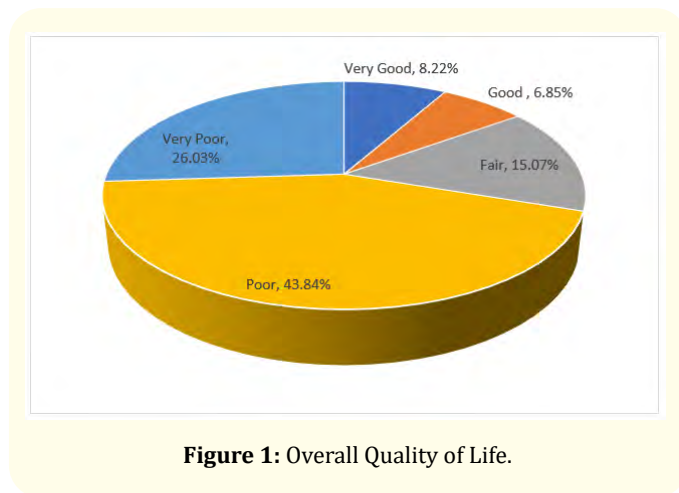


Figure 1: Overall Quality of Life.

Variable	Frequency	Percentage (%)
Have you experienced photodermatoses (sun-induced skin disorders)?		
Yes	71	97.26
No	2	2.74
*If yes, what type of photodermatoses have you experienced? (Multiple answers possible) (n = 303*)		
Solar lentigo	54	17.82
Polymorphous light eruption	62	20.46
Photoallergic eruption	69	22.77
Solar urticaria	7	2.31
Actinic prurigo	11	3.63
Photoaging	28	9.24
Actinic keratosis	59	19.47
Skin cancer	10	3.30
Others	3	0.99
If yes, how many times have you experienced skin problems related to sunlight exposure in the last one year?		

None	2	2.74
Once	2	2.74
Twice	1	1.37
Thrice	13	17.81
Four times	9	12.33
Five times	13	17.81
More than 5 times	33	45.21
How would you rate the severity of your skin problems?		
Very Mild	8	10.96
Mild	13	17.81
Moderate	19	26.03
Severe	23	31.51
Very Severe	10	13.70
*What measures do you take to protect your skin from the sun? (Multiple responses possible) (n = 176*)		
Wearing sun-protective clothing	68	38.64
Using sunscreen	21	11.93
Using Umbrella	19	10.80
Limiting time outdoors	63	35.80
Others	5	2.84
How frequently do you use these protective measures?		
Always	11	15.07
Often	22	30.14
Sometimes	38	52.05
Rarely	2	2.74
Never	00	0.00
Do you have access to dermatological care?		
Yes	69	94.52
No	4	5.48
If yes, how often do you visit a dermatologist?		
Regularly	13	17.81
Occasionally	51	69.86
Rarely	5	6.85
Never	00	0.00

**Table 3:** Photodermatoses in People with Albinism.

\* = Multiple responses

Variable	Frequency	Percentage (%)
Have you ever received any support?		
Yes	73	100.00
No	00	0.00
*What kind of support do you receive to manage your albinism and photodermatoses? (Multiple answers possible) (n = 174*)		
Medical/Healthcare	20	11.49
Family	36	20.69
Community	3	1.72
Governmental aid	42	24.14
Non-Governmental Organizations (NGOs)	73	41.95
Others	00	0.00
How satisfied are you with the support you receive?		
Very satisfied	6	8.22
Satisfied	14	19.18
Neutral	7	9.59
Unsatisfied	28	38.36
Very unsatisfied	18	24.66
Have you ever experienced discrimination or stigma due to your condition?		
Yes	70	95.89
No	3	4.11
How would you rate the access to healthcare services in your community?		
Very Good	14	19.18
Good	9	12.33
Fair	13	17.81
Poor	20	27.40
Very Poor	17	23.29
How knowledgeable do you feel your healthcare providers are about albinism and related skin conditions?		
Not at all	00	0.00
Slightly knowledgeable	3	4.11
Moderately knowledgeable	25	34.25
Well knowledgeable	35	47.95
Extremely knowledgeable	10	13.70

**Table 4:** Support and Access to Healthcare.

\* = Multiple responses

Demographic Information	Overall Quality of Life					X <sup>2</sup>	P-value
	Very Good (%)	Good (%)	Neutral (%)	Poor (%)	Very Poor (%)		
Age (in years)						7.735	0.015*
Below 20	00 (0.00)	1 (3.85)	2 (7.69)	12 (46.15)	11 (42.31)		
20-29	1 (7.69)	00 (0.00)	1 (7.69)	7 (53.85)	4 (30.77)		
30-39	00 (0.00)	1 (7.14)	2 (14.29)	7 (50.00)	4 (28.57)		
40 – 49	00 (0.00)	1 (9.09)	4 (36.36)	6 (54.55)	00 (0.00)		
50 – 59	3 (50.00)	1 (16.67)	2 (33.33)	00 (0.00)	00 (0.00)		
60 and above	2 (66.67)	1 (33.33)	00 (0.00)	00 (0.00)	00 (0.00)		
Marital Status						6.656	0.009*
Single	00 (0.00)	00 (0.00)	3 (5.88)	30 (58.82)	18 (35.29)		
Married	6 (30.00)	5 (25.00)	8 (40.00)	1 (5.00)	00 (0.00)		
Separated/Divorced/Widowed	00 (0.00)	00 (0.00)	00 (0.00)	1 (50.00)	1 (50.00)		
Level of Education						8.117	0.011*
No Formal Education	00 (0.00)	00 (0.00)	00 (0.00)	1 (25.00)	3 (75.00)		
Primary	00 (0.00)	00 (0.00)	2 (5.56)	19 (52.78)	15 (41.67)		
Secondary	2 (10.53)	3 (15.79)	5 (26.32)	8 (42.11)	1 (5.26)		
Tertiary	4 (28.57)	2 (14.29)	4 (28.57)	4 (28.57)	00 (0.00)		
Religion						2.287	0.917
Islam	3 (8.82)	1 (2.94)	5 (14.71)	15 (44.12)	10 (29.41)		
Christianity	3 (9.09)	3 (9.09)	6 (18.18)	14 (42.42)	7 (21.21)		
Others	00 (0.00)	1 (16.67)	00 (0.00)	3 (50.00)	2 (33.33)		
What type of albinism do you have? (If known)						2.382	0.893
Oculocutaneous albinism (OCA)	6 (8.57)	4 (5.71)	10 (14.29)	31 (44.29)	19 (27.14)		
X-linked ocular albinism (XLOA)	00 (0.00)	1 (100.00)	00 (0.00)	00 (0.00)	00 (0.00)		
Hermansky-Pudlak Syndrome (HPS)	00 (0.00)	00 (0.00)	00 (0.00)	00 (0.00)	00 (0.00)		
Chediak-Higashi Syndrome	00 (0.00)	00 (0.00)	00 (0.00)	00 (0.00)	00 (0.00)		
Others	00 (0.00)	00 (0.00)	00 (0.00)	00 (0.00)	00 (0.00)		
I don't know	00 (0.00)	00 (0.00)	1 (50.00)	1 (50.00)	00 (0.00)		

**Table 5:** Effect of Demographics on the Quality of Life of Albinos.



Photodermatoses in People with Albinism	Overall Quality of Life					X <sup>2</sup>	P-value
	Very Good	Good	Neutral	Poor	Very Poor		
Have you experienced photodermatoses (sun-induced skin disorders)?						9.892	0.000*
Yes	5 (7.04)	4 (5.63)	11 (15.49)	32 (45.07)	19 (26.76)		
No	1 (50.00)	1 (50.00)	00 (0.00)	00 (0.00)	00 (0.00)		
How would you rate the severity of your skin problems?						7.644	0.001*
Very Mild	3 (37.50)	2 (25.00)	3 (37.50)	00 (0.00)	00 (0.00)		
Mild	3 (23.08)	3 (23.08)	7 (53.85)	00 (0.00)	00 (0.00)		
Moderate	00 (0.00)	00 (0.00)	1 (5.26)	10 (52.63)	8 (42.11)		
Severe	00 (0.00)	00 (0.00)	00 (0.00)	19 (82.61)	4 (17.39)		
Very Severe	00 (0.00)	00 (0.00)	00 (0.00)	3 (30.00)	7 (70.00)		
How frequently do you use protective measures?						8.312	0.008*
Always	3 (27.27)	2 (18.18)	5 (45.45)	1 (9.09)	00 (0.00)		
Often	2 (9.09)	3 (13.64)	5 (22.73)	11 (50.00)	1 (4.55)		
Sometimes	1 (2.62)	00 (0.00)	1 (2.63)	20 (52.63)	16 (42.11)		
Rarely	00 (0.00)	00 (0.00)	00 (0.00)	00 (0.00)	2 (100.00)		
Never	00 (0.00)	00 (0.00)	00 (0.00)	00 (0.00)	00 (0.00)		
Do you have access to dermatological care?						8.994	0.000*
Yes	6 (8.70)	5 (7.25)	11 (15.94)	31 (44.93)	16 (23.19)		
No	00 (0.00)	00 (0.00)	00 (0.00)	1 (25.00)	3 (75.00)		
How often do you visit a dermatologist?						7.945	0.039*
Regularly	2 (15.38)	2 (15.38)	7 (53.85)	2 (15.38)	00 (0.00)		
Occasionally	4 (7.84)	3 (5.88)	3 (5.88)	27 (52.94)	14 (27.45)		
Rarely	00 (0.00)	00 (0.00)	1 (20.00)	2 (40.00)	2 (40.00)		
Never	00 (0.00)	00 (0.00)	00 (0.00)	1 (25.00)	3 (75.00)		

**Table 6:** Effect of Photodermatoses in People with Albinism on their Quality of Life.



Support and Access to Healthcare	Overall Quality of Life					X <sup>2</sup>	P-value
	Very Good	Good	Neutral	Poor	Very Poor		
Have you ever received any support?						9999	8.923
Yes	6 (8.22)	5 (6.85)	11 (15.07)	32 (43.84)	19 (26.03)		
No	00 (0.00)	00 (0.00)	00 (0.00)	00 (0.00)	00 (0.00)		
How satisfied are you with the support you receive?						6.963	0.013*
Very Satisfied	3 (50.00)	3 (50.00)	00 (0.00)	00 (0.00)	00 (0.00)		
Satisfied	3 (21.43)	2 (14.29)	7 (50.00)	2 (14.29)	00 (0.00)		
Neutral	00 (0.00)	00 (0.00)	3 (42.86)	4 (57.14)	00 (0.00)		
Unsatisfied	00 (0.00)	00 (0.00)	1 (3.57)	16 (57.14)	11 (39.29)		
Very unsatisfied	00 (0.00)	00 (0.00)	00 (0.00)	10 (55.56)	8 (44.44)		
Have you ever experienced discrimination or stigma due to your condition?						8.356	0.002
Yes	4 (5.71)	4 (5.71)	11 (15.71)	32 (45.71)	19 (27.14)		
No	2 (66.67)	1 (33.33)	00 (0.00)	00 (0.00)	00 (0.00)		

**Table 7:** Effect of Support and Access to Healthcare on the Quality of Life of Albinos.

**Discussion**

The study aimed to explore the relationship between photodermatoses and the quality of life in individuals living with albinism. Albinism is a genetic condition characterized by reduced melanin production, which leads to hypopigmentation in the skin, hair, and eyes [13]. A critical issue for individuals with albinism is skin vulnerability to the sun’s ultraviolet rays, often leading to photodermatoses (sun-induced skin disorders) [6]. This issue is particularly salient in regions such as Ogun State, Nigeria, where the intensity of sun exposure is high.

The age distribution of the participants suggests a predominantly younger demographic. A considerable percentage of the participants (35.61%) are below 20 years of age, while 17.81% are aged 20-29 years, and 19.18% are aged 30-39 years.

Only a minority of the participants are aged 40 years and above. This youthful demographic could have implications for the results, as younger individuals may experience different challenges and have different perceptions of their quality of life compared to older individuals [14].

The majority of participants are single (69.86%), which might also have significant implications for their quality of life and experience with photodermatoses, as married individuals often have additional support networks that could potentially ease their burden [15].

Most of the participants have some level of formal education. Only a small fraction (5.48%) reported having no formal education. The majority (35.61%) had primary level education, while 26.03%

had secondary education, and 19.18% had tertiary education. This indicates that most individuals with albinism in this sample have access to education, which could influence their understanding of their condition and the strategies they use to manage it [7].

The religious breakdown shows an almost equal distribution between Islam (46.58%) and Christianity (45.21%). The impact of religious beliefs on the perception and management of albinism could be a fascinating avenue for further research [16].

The type of albinism reported by participants provides crucial insights into the nature of albinism in Ogun State. An overwhelming majority of the respondents (95.89%) reported having Oculocutaneous albinism (OCA), while only 1.37% reported having X-linked ocular albinism (XLOA). No participant reported having Hermansky-Pudlak Syndrome (HPS) or Chediak-Higashi Syndrome, and 2.74% reported not knowing their type of albinism. This information is significant because different types of albinism are associated with varying levels of disability, risk of photodermatoses, and potential impacts on quality of life [13]. Given the dominant presence of OCA among the respondents, the results of this research are particularly important. OCA, a form of albinism involving the skin, hair, and eyes, is known to increase susceptibility to skin damage from the sun, often leading to Photodermatoses [13]. Sunburn, chronic sun damage, skin cancer, and other related conditions can significantly decrease the quality of life and increase morbidity and mortality among these individuals [1]. Therefore, the study's findings shed light on a significant public health issue in this Nigerian state.

Quality of life (QoL) is a multifaceted concept, encapsulating a variety of dimensions that include physical health, psychological wellbeing, personal beliefs, social relationships, and environmental factors [17]. For individuals with albinism, the QoL is often negatively impacted due to associated health and social challenges. One key health issue for people with albinism, which this study focuses on, is Photodermatoses, a group of conditions triggered by an abnormal reaction to sunlight exposure [18]. It is crucial to assess this quality of life, as albinism presents unique challenges for those who experience it, particularly in terms of physical health, mental health, societal acceptance, and personal relationships [19].

The Quality-of-Life assessment results suggest varying degrees of satisfaction and dissatisfaction among the respondents. From

the results, a clear majority (69.86%) disagreed with the statement "I am satisfied with my physical health." This is not surprising, given the significant physical challenges often faced by individuals with albinism, including photodermatoses, visual impairments, and higher risks of skin cancer [3]. This high level of dissatisfaction suggests that people with albinism in the area experience substantial physical health challenges, likely related to their skin condition and susceptibility to sun-related harm [20]. Such physical discomfort significantly undermines their quality of life, demonstrating the urgent need for improved health management strategies for this population.

With regards to mental health, the data shows a contrasting picture. 73.98% of respondents agreed or strongly agreed that they are content with their mental health. It suggests that despite the physical challenges, individuals with albinism in this study are relatively resilient in terms of their mental well-being. Alternatively, this could indicate a strong community or familial support network that fosters mental resilience [21]. This resilience, however, may not be universal as some studies have indicated high levels of psychological distress among individuals with albinism [22].

When it comes to managing daily routine, a mixed reaction was observed. Approximately 42.47% agreed they can manage their daily routine, while 42.47% disagreed. This suggests that the physical challenges of albinism may make routine tasks more difficult for some, but not for all individuals. Some research has shown that adaptive strategies and access to supportive resources can significantly improve daily living skills in people with albinism [23]. The split in this result could signify varying degrees of functional impairment or access to supportive resources in this population. It could be insightful to further explore the factors influencing this disparity in future studies [24].

The perceived relationship quality with friends and family was generally positive, with 68.5% agreeing or strongly agreeing that they have good relationships. This outcome suggests the importance of social support for individuals with albinism, which aligns with previous research showing the vital role of family and friends in mitigating the psychosocial impacts of visible differences [25].

However, the ability to participate in social activities and community acceptance were both notably low. Over 50% of the

respondents disagreed or strongly disagreed they are able to partake in social events, and 73.97% felt the same about their acceptance in the community. This reflects a significant social isolation that individuals with albinism often face, which can be attributed to societal prejudice, discrimination, and misconceptions about albinism [26].

Financial distress appears to be a significant issue, as 88.36% disagreed or strongly disagreed they are comfortable with their financial situation. This financial insecurity could stem from difficulties in finding or maintaining employment due to the physical limitations of albinism, which is supported by 84.94% of participants acknowledging that their condition affects their ability to work or study [1]. This suggests that albinism might be imposing a financial burden, which could be due to high medical expenses, reduced income capacity, or inability to engage in certain types of employment [27].

Participants overwhelmingly agreed that their condition affects their ability to work or study (85%) and personal relationships (74%). This further emphasizes the considerable social impact of albinism, which can limit educational and career opportunities, and hinder the formation and maintenance of close personal relationships [28].

Interestingly, while 74% agreed that their condition affects their personal relationships, the impact on emotional well-being was somewhat ambiguous. While 74% agreed or strongly agreed that their condition impacts their emotional health, only 36.3% agreed or strongly agreed they often have negative feelings like sadness, desperation, anxiety, and depression. This suggests that while their condition poses emotional challenges, this does not always translate into negative feelings, possibly reflecting the respondents' resilience or coping strategies [29]. However, the findings indicate a significant emotional burden of living with albinism, which aligns with previous research showing a high prevalence of psychological distress in this population [30].

The overall satisfaction with the quality of life was quite low, with only 15.07% agreeing or strongly agreeing they are happy with their overall quality of life. This low percentage indicates that despite some areas of relative resilience, the overall QoL for individuals with albinism in Ogun State is suboptimal [31]. This emphasizes

the multidimensional impact of albinism on individuals' quality of life and underscores the need for comprehensive interventions addressing physical, mental, and social aspects of life [32].

In this study, nearly 70% of respondents rated their quality of life as poor or very poor (Figure 1). This aligns with existing literature suggesting that people with albinism often experience a lower QoL due to their health condition [33]. The challenges associated with albinism, including visual impairments and susceptibility to skin diseases, along with societal stigma and discrimination, can significantly impact the QoL of these individuals [34]. On the other hand, this statistic is disconcerting when compared to global statistics, where the average quality of life is typically reported as much higher [35]. This discrepancy may reflect the additional burdens faced by people with albinism, including the physical discomfort caused by photodermatoses and the social and psychological stress of living with a visible difference.

Moreover, the societal and cultural perceptions of albinism in Nigeria, specifically, and Africa, generally, are often negative and based on misunderstanding and superstition [36]. Discrimination, stigma, and even physical attacks are unfortunately common experiences for people with albinism in Africa, which undoubtedly impacts their perceived quality of life [37].

Another significant concern is the lack of effective treatments or preventive measures for photodermatoses in people with albinism. Skin protection, such as the use of sunscreens, clothing, and hats, is essential but can be challenging due to economic and accessibility issues [38]. It is essential to further explore ways of managing photodermatoses to improve the quality of life in this population.

According to the results (Table 3), a vast majority (97.26%) of the participants experienced photodermatoses, which aligns with previous studies suggesting that people with albinism are prone to skin disorders resulting from sunlight exposure [39]. Different types of photodermatoses reported include solar lentigo, polymorphous light eruption, photoallergic eruption, solar urticaria, actinic prurigo, photoaging, actinic keratosis, skin cancer, and others.

Solar lentigo (17.82%), polymorphous light eruption (20.46%), photoallergic eruption (22.77%), and actinic keratosis (19.47%)

were the most commonly reported photodermatoses. These findings mirror previous studies [39] that demonstrate the increased risk of various photodermatoses in individuals with albinism due to their lack of protective melanin pigment.

Notably, skin cancer was reported by 3.3% of the participants. While this percentage might seem small, it is a concerning figure considering the severe health implications of skin cancer [27]. It is important to emphasize the need for regular dermatological screenings and sun protective measures among this population to prevent the development and progression of skin cancer.

Most participants reported experiencing skin problems related to sunlight exposure more than five times (45.21%) in the past year, indicating a high frequency of photodermatosis episodes. This suggests a significant impact on their quality of life, requiring regular management and treatment [40].

In terms of the severity of skin problems, most of the participants rated their problems as 'severe' (31.51%) or 'moderate' (26.03%). This underscores the negative impact of photodermatoses on individuals with albinism, which may not only affect their physical health but also their psychological wellbeing due to the discomfort and cosmetic disfigurement associated with these conditions [27,40].

With regard to protective measures, most participants reported wearing sun-protective clothing (38.64%) and limiting time outdoors (35.80%), while fewer reported using sunscreen (11.93%) and using an umbrella (10.80%). Given the benefits of sunscreen in preventing photodermatoses, it is concerning to see a relatively low usage rate. This might be due to various factors such as lack of awareness, affordability, or accessibility, and this warrants further investigation.

Most participants reported that they 'sometimes' use these protective measures (52.05%). This finding suggests that although individuals with albinism are aware of some sun protective measures, they may not be consistently adhering to them. Efforts to enhance education about the importance of regular sun protection and how to effectively implement these strategies are necessary.

In terms of access to dermatological care, a large majority (94.52%) reported having access, which is encouraging. Most

participants (69.86%) reported visiting a dermatologist 'occasionally', while a smaller percentage visit 'regularly' (17.81%). Regular check-ups are crucial for early detection and treatment of photodermatoses [41].

According to the research findings (Table 4), a majority of respondents receive support for their albinism and photodermatoses from non-governmental organizations (NGOs) (41.95%), government aid (24.14%), and family (20.69%). However, medical or healthcare support is received by only 11.49% of the participants. This is in line with the findings of Braathen and Ingstad [42], who found that in many African countries, healthcare services often fall short of effectively supporting PWAs, primarily due to a lack of understanding and knowledge about the condition.

On satisfaction with support received, a sizable proportion of respondents reported being unsatisfied (38.36%) or very unsatisfied (24.66%). This finding is indicative of the urgent need for improvements in services and support for PWAs in Nigeria, as the high level of dissatisfaction underscores a considerable gap in service delivery and support structures. Similar findings were echoed in a study by Cruz-Inigo, *et al.* [34], who underscored that in many developing countries, the provision of support for PWAs is often inadequate.

The data also reveal a high incidence of discrimination or stigma due to the condition of albinism, with 95.89% of respondents affirming such experiences. This is a clear indication of the extent of social stigma associated with albinism, a reality also noted in research by Baker, *et al.*, [36], who pointed out that societal misunderstandings and misconceptions about albinism can often lead to stigma and discrimination.

Respondents rated their access to healthcare services in their community predominantly as poor (27.40%) or very poor (23.29%). This is a glaring indictment of the healthcare infrastructure in place and indicates that significant improvements are needed in healthcare accessibility for PWAs. Lund *et al.* [3] pointed out similar challenges in her work, where she concluded that PWAs in many African countries struggle with accessing healthcare services due to financial constraints, transportation issues, and inadequate healthcare infrastructure.

When it comes to healthcare providers' knowledge about albinism and related skin conditions, 47.95% of the respondents deemed them as well knowledgeable, while 34.25% viewed them as moderately knowledgeable. The fact that no respondents found their healthcare providers not knowledgeable at all is an encouraging sign. Nonetheless, the percentages for those who found their healthcare providers to be only slightly or moderately knowledgeable highlight the need for increased training and awareness among healthcare providers. These findings are consistent with the study by Mabula *et al.* [43], who noted that a lack of healthcare provider knowledge about albinism can often compromise the quality of care for PWAs.

One key result of this study is the significant effect of age on the quality of life of albinos ( $X^2 = 7.735$ ,  $p = 0.015$ ) (Table 5). The results showed that the youngest participants (below 20 years) had a notably low quality of life, with 42.31% of them reporting a very poor quality of life, and 46.15% reporting a poor quality of life. This trend generally lessened with age, with the percentage of participants reporting poor or very poor quality of life decreasing in each age bracket up to 60 years and above. A high percentage (66.67%) of the oldest participants (60 years and above) reported a very good quality of life, and none reported a poor or very poor quality of life. This outcome is in line with previous studies indicating that younger individuals with albinism often experience more significant social and psychological challenges compared to their older counterparts [32]. This may be due to the social stigmatization and discrimination they face, which can lead to social isolation, reduced self-esteem, and poor academic performance [1].

Marital status was also a significant factor affecting the quality of life of albinos ( $X^2 = 6.656$ ,  $p = 0.009$ ). Single participants were more likely to report a poor (58.82%) or very poor (35.29%) quality of life compared to their married counterparts, who were more likely to report a good (25%) or very good (30%) quality of life. This finding suggests that married individuals with albinism may have better social support, contributing to a better quality of life, which echoes the findings of Aquaron *et al.* [7]. Previous studies have shown that social support, including from a spouse, can have a profound impact on the perceived quality of life in people living with various health conditions [44]. This trend could possibly reflect the importance of social support in improving the quality of life in individuals with albinism.

There was a significant association between the level of education and the quality of life of albinos ( $X^2 = 8.117$ ,  $p = 0.011$ ). Those with tertiary education reported the highest rate of good (14.29%) and very good (28.57%) quality of life, whereas those without formal education reported the poorest quality of life. The link between education level and quality of life has been reported in previous studies. As Braathen and Ingstad [42] pointed out, education plays a crucial role in reducing poverty and enhancing self-confidence, self-esteem, and life satisfaction among individuals with albinism. A lack of education can significantly affect their socioeconomic status and employment opportunities, leading to a lower quality of life.

Religion and type of albinism had no statistically significant effect on the quality of life among the participants. The p-values for both factors were greater than 0.05 (religion:  $p = 0.917$ , type of albinism:  $p = 0.893$ ), suggesting no significant difference in the quality of life among different religious groups and different types of albinism.

The research demonstrates that people with albinism who have experienced photodermatoses report a lower quality of life compared to those who have not (Table 6). The significant  $X^2$  (9.892) and p-value (0.000) support this association. Indeed, 45.07% of respondents who have experienced photodermatoses reported a 'poor' quality of life, while 26.76% indicated a 'very poor' quality of life. This aligns with previous studies which showed that people with photodermatoses experience a significant decrease in their quality of life, due to factors such as physical discomfort, social stigmatization, and psychological stress [45].

There is a clear association between the severity of skin problems and the overall quality of life, with an  $X^2$  value of 7.644 and a p-value of 0.001. The data suggests that as the severity of the skin problems increase, the quality of life decreases significantly. This could be due to increased physical discomfort, increased frequency of treatment, and the psychological impact of having a visible skin disorder [46].

The research also indicated that the frequency of using protective measures is significantly associated with quality of life, as evidenced by an  $X^2$  value of 8.312 and a p-value of 0.008. Individuals who reported always using protective measures were



more likely to rate their quality of life as 'good' or 'very good'. This could be due to the fact that protective measures can reduce the symptoms and severity of photodermatoses, thereby mitigating its impact on quality of life [47].

Access to dermatological care is another significant factor in determining the quality of life. With an  $X^2$  value of 8.994 and a p-value of 0.000, the research indicates that those with access to dermatological care report a better quality of life compared to those without. This underscores the importance of healthcare accessibility in managing skin disorders and in improving the overall quality of life [48].

The study showed a significant association between the frequency of visiting a dermatologist and quality of life, with an  $X^2$  value of 7.945 and a p-value of 0.039. Individuals who visited a dermatologist regularly had a better quality of life than those who rarely or never visited. This might be because regular visits allow for better management and control of the condition, leading to improved quality of life [49].

The results further showed that there is a significant relationship between receiving support and quality of life ( $X^2 = 8.923$ ,  $p < 0.01$ ), satisfaction with support and quality of life ( $X^2 = 6.963$ ,  $p < 0.05$ ), and experiencing discrimination or stigma due to the condition and quality of life ( $X^2 = 8.356$ ,  $p < 0.01$ ).

The first test indicates that individuals who receive support have diverse ratings of quality of life. However, it is noteworthy that a large percentage rated their quality of life as either poor (43.84%) or very poor (26.03%). This may suggest that while support is received, it might not be adequate or appropriate in addressing the challenges faced by individuals with albinism, thereby affecting their quality of life negatively. This echoes the findings of Hong, *et al.* [1], who emphasized the need for support systems to be well-tailored to the unique needs of individuals to improve their quality of life.

Further examining the quality of support, the research indicates a significant relationship between the satisfaction derived from the support and the quality of life. Individuals who were very satisfied with the support they received rated their quality of life as either very good or good. Conversely, those who were unsatisfied or very unsatisfied with the support had a tendency to rate their quality

of life as poor or very poor. This underscores the point made by Molina, *et al.* [50], who argued that the effectiveness and adequacy of the support systems significantly impact the quality of life of individuals with albinism.

Finally, the data also reflects a significant association between the experience of discrimination or stigma due to the condition and the quality of life. Individuals who had experienced discrimination or stigma mostly rated their quality of life as poor or very poor. This resonates with the findings of Harris, *et al.* [51], who found that discrimination and stigma can have detrimental effects on the mental and social aspects of quality of life. The results underscore the importance of combating discrimination and stigma in improving the quality of life for people with albinism.

## Conclusion and Recommendations

The findings of this study highlight the ongoing challenges faced by people with albinism in Ogun State, Nigeria, where the majority of respondents reported a poor or very poor quality of life. While some positive elements such as relatively knowledgeable healthcare providers are present, several challenges persist. These include inadequate healthcare access, dissatisfaction with support, and widespread experiences of stigma and discrimination. The study revealed that age, marital status, and level of education have a significant effect on the quality of life of individuals with albinism. Similarly, photodermatoses significantly impact the quality of life of people with albinism. The results further highlight the significant roles that support, satisfaction with that support, and experiences of discrimination and stigma play in shaping the quality of life of people with albinism. This study adds to the academic literature by emphasizing that providing support is not sufficient on its own – the quality, adequacy, and appropriateness of this support are also pivotal. Furthermore, addressing societal discrimination and stigma towards individuals with albinism is of paramount importance to improve their quality of life. This research underscores the need for targeted interventions to improve health outcomes and quality of life for individuals with albinism. Such interventions should consider both the physical health impacts of albinism, such as photodermatoses, as well as the socio-cultural factors that may exacerbate these issues. The findings call for enhanced health education and promotion strategies targeting sun-protective measures, as well as increased accessibility to regular dermatological care. There is a clear need

for multi-faceted and context-specific interventions, encompassing increased government support, improved healthcare services, and heightened societal awareness about albinism. Further research should focus on developing strategies and policies that can improve the quality of life of individuals with albinism, particularly among younger individuals, those who are single, and those with low education levels.

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