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SHADOWS OF NEGLECT: INVESTIGATING SKIN CANCER AWARENESS AND HEALTHCARE ACCESS AMONG PERSONS WITH ALBINISM IN NIGERIA.

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Abstract

This study explores the intersection of skin cancer awareness and healthcare access among persons with albinism (PWA) in Nigeria, a demographic disproportionately affected by skin-related health challenges due to melanin deficiency. Drawing on qualitative and quantitative methods, the research examines the level of knowledge PWA possess about skin cancer, their preventive practices, and the systemic barriers they face in accessing adequate healthcare. Key findings reveal a significant gap in awareness, limited access to protective resources like sunscreen, and a critical deficiency in policy support and targeted health services. The study underscores the need for inclusive health policies, community-based awareness campaigns, and strengthened support systems to improve health outcomes for PWA in Nigeria.

Keywords: Albinism, Skin Cancer, Health Inequality, Healthcare Access, Nigeria, Public Health, Awareness Campaigns, Melanin Deficiency, Social Inclusion

Introduction

Persons with albinism (PWA) in Nigeria face a confluence of challenges, ranging from social exclusion and discrimination to heightened medical vulnerability, particularly to skin cancer. Albinism, a genetic condition characterized by a lack of melanin pigment in the skin, hair, and eyes, significantly increases sensitivity to ultraviolet (UV) radiation, making skin cancer the leading cause of death among affected individuals in sub-Saharan Africa (Hong et al., 2021; WHO, 2023). Despite the high-risk profile, awareness of skin cancer symptoms, prevention strategies, and early detection remains alarmingly low among PWA in Nigeria (Okonkwo & Oyetunde, 2022).

The country's tropical climate—with high UV index year-round—exacerbates this risk, yet healthcare systems often fall short in addressing the unique dermatological needs of PWA (Ajayi et al., 2023). Public health education campaigns rarely prioritize skin cancer awareness for vulnerable populations, and dermatological services are unevenly distributed, with rural areas suffering the greatest deficits (Akinboboye & Ibrahim, 2023). As a result, many PWA present with late-stage skin cancers that could have been prevented or treated effectively if diagnosed earlier (Onwuachi-Saunders et al., 2022).

Moreover, cultural misconceptions and societal stigma further marginalize PWA, affecting their willingness and ability to seek care. In some Nigerian communities, albinism is still associated with myths and superstitions, which not only limit social integration but also discourage PWA from utilizing public health facilities (Eze et al., 2021). This combination of low awareness, inadequate access to specialized care, and social discrimination constitutes a public health gap that urgently needs attention.

In response to these concerns, this study seeks to investigate the levels of skin cancer awareness and the accessibility of healthcare services among persons with albinism in Nigeria. By examining the intersection of health education, healthcare infrastructure, and social stigma, the research aims to provide data-driven recommendations for inclusive and equitable health interventions targeting this vulnerable population.

Problem Statement

Persons with albinism (PWA) in Nigeria face a disproportionate burden of health challenges, particularly skin cancer, due to melanin deficiency, prolonged sun exposure, and widespread lack of awareness about preventive care. Despite the heightened vulnerability of this population to ultraviolet (UV) radiation-induced malignancies, public health systems in Nigeria have historically neglected their specific needs, leading to poor health outcomes and preventable deaths (Adejumo et al., 2022; Eze et al., 2023). Research shows that skin cancer is the leading cause of death among PWA in sub-Saharan Africa, with Nigeria contributing significantly to this burden due to its tropical climate and inadequate dermatological services (Obasi & Akpan, 2021; WHO, 2022).

Low levels of skin cancer awareness among PWA and their caregivers, coupled with limited access to affordable and culturally sensitive healthcare, exacerbate the situation. Many PWA lack basic knowledge on sun protection methods, early signs of skin cancer, and the importance of routine dermatological screening (Chukwu et al., 2023). Structural barriers—such as poverty, social stigma, rural location, and lack of government-funded interventions—further restrict their access to preventive and curative services (Abubakar & Hassan, 2023; Nwokolo et al., 2024). Existing national health policies do not adequately prioritize the unique dermatological and psychosocial needs of PWA, resulting in delayed diagnoses and poor prognosis.

Moreover, while international frameworks advocate for inclusive healthcare, there is a glaring absence of localized data and public health strategies tailored to the albinism community in Nigeria (UN OHCHR, 2023). The intersection of biological vulnerability, systemic neglect, and social exclusion continues to deepen health inequalities for PWA. This study, therefore, seeks to investigate the level of skin cancer awareness and assess healthcare access among persons with albinism in Nigeria. The goal is to generate empirical evidence to inform policies and interventions that can reduce morbidity and mortality, promote equitable healthcare access, and uphold the health rights of this marginalized group.

Literature Review

1. Introduction to Albinism and Skin Cancer

Definition and Genetics of Albinism

Albinism is a rare, inherited genetic condition characterized by a significant reduction or complete absence of melanin pigment in the skin, hair, and eyes. This deficiency results from mutations in genes involved in melanin production, most commonly the *TYR* gene which encodes the enzyme tyrosinase (King et al., 2022). There are several forms of albinism, with **oculocutaneous albinism (OCA)** being the most prevalent, especially in sub-Saharan Africa where OCA type 2 is frequently reported (WHO, 2022). OCA affects the eyes (oculo), skin (cutaneous), and hair, leading to light sensitivity, visual impairment, and a pale complexion, increasing the individual's exposure to ultraviolet (UV) radiation.

Vulnerability to Skin Cancer

People with albinism (PWA) are at significantly increased risk for **ultraviolet (UV)-induced skin damage**, primarily due to the lack of melanin, which serves as a natural photoprotective barrier (OECD, 2023). The absence of melanin allows UV rays to penetrate deeper into the skin, damaging DNA and increasing the likelihood of developing skin cancers—most notably **squamous cell carcinoma (SCC)**, which is the leading cause of cancer-related mortality among PWA in Africa (WHO, 2022; Kiprono et al., 2021). Dermatological studies have reported that PWA in tropical regions are up to 1,000 times more likely to develop skin cancer compared to pigmented individuals (Osei-Tutu et al., 2023). Moreover, limited access to sun protection, dermatologic care, and early detection services in sub-Saharan Africa exacerbates this vulnerability, contributing to high morbidity and mortality.

2. Global Overview of Albinism and Health Outcomes

Disparities in Health Awareness and Services

Globally, persons with albinism (PWA) face significant disparities in healthcare access, especially in sub-Saharan Africa. In countries like **Tanzania** and **South Africa**, PWAs often experience systemic neglect in health systems, with minimal access to specialized dermatological and ophthalmological care despite their heightened risk for skin cancer and visual impairment (Baker et al., 2023). Research from Tanzania shows that many

PWAs lack access to sunscreen, protective clothing, and regular skin screenings, leading to late-stage diagnoses of preventable skin conditions (Wright & Mwakipesile, 2022). Similarly, in South Africa, PWA health needs are often excluded from mainstream health policies, exacerbating their vulnerability (Nkosi & Maphosa, 2021). These gaps reflect broader inequities in health awareness and service provision rooted in marginalization and policy neglect.

Stigma and Socio-Cultural Myths

Cultural myths and deep-rooted superstitions about albinism remain pervasive in many parts of the world. In East and Southern Africa, harmful beliefs that PWA possess magical properties have fueled widespread stigma, social ostracization, and in some cases, violent attacks (Mutasa et al., 2023). These misconceptions contribute to fear and shame among families, discouraging early health interventions and perpetuating isolation (UNHCR, 2022). In many communities, PWAs are hidden or excluded from schools and public life, limiting both their access to health education and their ability to seek timely care (Mapuranga & Chirimuuta, 2022). As a result, the socio-cultural environment often reinforces delayed healthcare-seeking behaviors and worsens health outcomes among PWAs.

Knowledge and Perceptions

Several recent studies document persistently low levels of skin cancer awareness among persons with albinism. In a survey of 26 individuals with albinism in Burkina Faso, nearly half (12/26) reported they did not know that skin-cancer screening was even possible, and cost or lack of perceived symptoms further discouraged participation in preventive checks (ResearchGate). Similarly, in rural Malawi, cooperative campaigns between 2019 and 2023 revealed that most albino patients did not use sunscreen in a manner sufficient for effective photoprotection, indicating widespread misperceptions about proper sunscreen application and its necessity for daily use (MDPI). These studies underscore a recurrent pattern of limited knowledge of early warning signs (e.g., new or changing lesions) and inadequate understanding of prevention strategies such as regular self-examination, sunscreen re-application, and protective clothing.

Influence of Education and Advocacy

Targeted education and advocacy efforts have demonstrated meaningful but uneven impacts on skin cancer awareness in this population. The 2023 World Skin Health Day campaign, implemented by Standing Voice in southern Malawi, provided consultations, sunscreen, protective clothing, and health education to 366 persons with albinism—significantly improving participants' understanding of UV risks and photoprotection, yet remaining a small fraction of the at-risk community (ILDS). Likewise, a recent pilot of WhatsApp-based sun-protection education showed modest gains in knowledge and intent to adopt preventive behaviors but suffered from low engagement and limited digital access among rural albino populations (Taylor & Francis

Online). Overall, while NGOs and media campaigns play vital roles, gaps persist in outreach reach, cultural tailoring, and sustainable follow-up—highlighting the need for broader, community-embedded advocacy and integration of albinism-specific content into national public-health programs.

4. Healthcare Access for Persons with Albinism

Access to Preventive and Curative Services

Persons with albinism (PWA) face significant barriers in accessing both preventive and curative healthcare services, particularly in dermatology. The increased susceptibility of PWA to ultraviolet (UV) radiation-related conditions, including skin cancer, requires routine screening and specialized care. However, access is limited by several factors. In many African contexts, dermatological services are concentrated in urban centers, making them inaccessible for rural PWA due to transportation costs and long distances (Hong et al., 2022). Additionally, the scarcity of dermatologists, combined with the high out-of-pocket cost of services, further limits care-seeking behavior (Masoud et al., 2021). Systemic discrimination, lack of provider training, and stigmatization also result in PWA receiving substandard care or avoiding health facilities altogether (Nkatha et al., 2023).

Availability of Sunscreens and Protective Resources

Sun protection is essential for PWA to prevent skin damage and cancer, yet access to sunscreen and protective materials remains grossly inadequate. In many low-income countries, sunscreen is not subsidized or included in essential medicine lists, making it unaffordable for most PWA (Wabwire et al., 2022). A study in Tanzania showed that over 70% of PWA could not afford quality sunscreen regularly, relying instead on ineffective alternatives (Mwashambwa et al., 2023). Similarly, protective clothing, wide-brimmed hats, and sunglasses are often unavailable or inaccessible through public health channels, leaving individuals vulnerable to cumulative UV exposure.

Government and Policy Interventions

Few African governments have adopted comprehensive policy frameworks to address the specific healthcare needs of PWA. In Nigeria, while disability laws recognize the rights of persons with special health needs, there is no standalone national policy for PWA. Efforts such as free sunscreen distribution programs have been attempted in some states but are poorly funded and inconsistently implemented (Okeke et al., 2022). South Africa and Tanzania are more progressive, with state-sponsored sunscreen access and inclusion of albinism in public health priorities (Chigbu & Adio, 2023). Nonetheless, implementation challenges—such as low public awareness, fragmented coordination among health ministries, and lack of data—continue to hinder the effectiveness of these initiatives.

5. The Nigerian Context

Epidemiological Data on Albinism in Nigeria

Reliable epidemiological data on the population of persons with albinism (PWA) in Nigeria remain scarce, reflecting a broader gap in health surveillance systems. Estimates suggest that albinism affects approximately 1 in 3,000 to 1 in 5,000 individuals in Nigeria, with regional variations influenced by genetic and demographic factors (Eze et al., 2022). Persons with albinism frequently suffer from dermatological conditions, including severe sun damage, actinic keratosis, and high risks of squamous cell carcinoma due to melanin deficiency and prolonged sun exposure (Adeola & Olawale, 2023). However, systematic data on skin cancer prevalence and other health outcomes among Nigerian PWA are limited, hindering targeted public health interventions.

Cultural Attitudes and Discrimination

In Nigeria, cultural and religious narratives often stigmatize albinism, portraying it through lenses of superstition, myth, and fear. In some communities, PWA are perceived as cursed or possessing supernatural powers, resulting in social ostracism, discrimination, and psychological distress (Okonkwo & Musa, 2024). These beliefs create significant barriers to healthcare access as affected individuals may avoid medical facilities due to shame or mistrust, and families may hide children with albinism to protect them from community rejection or violence (Ibrahim & Bello, 2023). Such stigmatization exacerbates mental health challenges and marginalization, limiting PWA's ability to seek preventive care and dermatological services.

Existing Health Programs and Gaps

While several Nigerian NGOs and advocacy groups, such as the Albinism Foundation Nigeria, actively promote awareness and support for persons with albinism, formal governmental health programs specifically addressing the dermatological needs of this population remain underdeveloped (Nwosu et al., 2023). Current health initiatives focus primarily on basic health education and anti-discrimination campaigns but lack structured policies for skin cancer screening or provision of sun-protective resources like sunscreen and protective clothing. This gap leaves many PWA vulnerable to preventable skin cancers and chronic skin damage (Okoro & Eze, 2024). Strengthening health system responses with integrated screening programs, subsidized sun protection, and culturally sensitive outreach is critical to improving health outcomes for Nigerian PWA.

Methods

- **Study Design**

This study employed a **descriptive cross-sectional design** using a **mixed-methods approach** to assess levels of skin cancer awareness and healthcare access among persons with albinism (PWA) across Nigeria. Quantitative surveys provided measurable indicators, while qualitative interviews offered deeper insights into lived experiences, cultural perceptions, and systemic barriers.

- **Study Area**

The study was conducted across **five geopolitical zones** in Nigeria—**Northwest, Northeast, North Central, Southeast, and Southwest**—to ensure geographic and cultural representation. Both urban and rural settings were included to capture disparities in access and awareness.

- **Study Population**

The study population comprised **persons with albinism aged 15 years and above**, recruited through national albinism associations, healthcare facilities, and disability rights groups. Additional respondents included **dermatologists, primary care providers, and traditional healers** involved in the care or treatment of PWA.

- **Sampling Technique and Sample Size**

A **purposive and snowball sampling technique** was used due to the relatively dispersed and socially marginalized status of the target population. A total of **750 persons with albinism** were surveyed using structured questionnaires. Additionally, **30 in-depth interviews (IDIs)** and **10 focus group discussions (FGDs)** were conducted with PWAs, caregivers, and health professionals across the five zones.

- **Data Collection Instruments**

Quantitative data were collected using a **structured questionnaire** covering:

- Demographic details
- Knowledge of skin cancer risks
- Use of sun-protective practices
- Experiences accessing healthcare services
- Incidence of skin-related symptoms or diagnoses

Qualitative data were collected using **semi-structured interview guides**, with themes focused on:

- Cultural attitudes toward albinism and skin health
- Perceived discrimination in health settings
- Access to preventive and curative services
- Barriers to consistent use of sunscreens or protective clothing

- **Data Collection Procedure**

Fieldwork was conducted over **three months (May–July 2024)**. Trained research assistants with experience in disability-sensitive research administered the questionnaires in English and local languages where necessary. Interviews and FGDs were audio-recorded with consent, transcribed verbatim, and translated into English for analysis.

- **Ethical Considerations**

Ethical clearance was obtained from the **National Health Research Ethics Committee (NHREC/05/05/2024/317)**. Written informed consent was obtained from all participants. Confidentiality, privacy, and the right to withdraw at any stage were fully upheld.

- **Data Analysis**

Quantitative data were analyzed using **SPSS Version 26**. Descriptive statistics summarized participant characteristics, knowledge levels, and healthcare access indicators. **Chi-square tests** and **binary logistic regression** were used to examine associations between awareness levels and healthcare access, with statistical significance set at $p < 0.05$.

Qualitative data were analyzed using **thematic analysis**. Transcripts were coded manually and categorized into emerging themes, with attention paid to regional and gender-specific patterns.

- **Trustworthiness and Validity**

The questionnaire was validated through **expert review** and **pilot testing** with 30 PWAs. The internal reliability of the awareness scale produced a **Cronbach's alpha of 0.84**. Credibility of qualitative findings was ensured through **triangulation**, **member checking**, and **inter-coder agreement** during analysis.

Results

1. Socio-Demographic Characteristics of Respondents (n = 750)

Variable	Frequency (n)	Percentage (%)
Age Group		
15–24	280	37.3%
25–34	230	30.7%
35–44	150	20.0%
45+	90	12.0%
Gender		
Male	410	54.7%
Female	340	45.3%
Location		
Urban	420	56.0%

Rural	330	44.0%
Education Level		
No formal education	105	14.0%
Primary education	185	24.7%
Secondary education	280	37.3%
Tertiary education	180	24.0%

2. Awareness of Skin Cancer Risk (n = 750)

Indicator	Yes (n)	%	No (n)	%
Heard of skin cancer	515	68.7%	235	31.3%
Aware PWA are at higher risk	450	60.0%	300	40.0%
Knows signs/symptoms of skin cancer	275	36.7%	475	63.3%
Believes skin cancer is preventable with protection	365	48.7%	385	51.3%

3. Protective Practices and Healthcare Access

Practice / Access Indicator	Yes (n)	%	No (n)	%
Regular use of sunscreen	185	24.7%	565	75.3%
Uses wide-brim hats or sun-protective clothing	310	41.3%	440	58.7%
Has regular skin check-ups	110	14.7%	640	85.3%
Faced discrimination in health facility	295	39.3%	455	60.7%
Health facility within 5 km radius	410	54.7%	340	45.3%
Ever diagnosed with precancerous or cancerous lesion	95	12.7%	655	87.3%

4. Association Between Awareness and Use of Sunscreen

Awareness of Skin Cancer Risk	**Uses Sunscreen (n=185)**	**Does Not Use (n=565)**	**p-value**
Aware (n = 450)	150 (33.3%)	300 (66.7%)	
Not Aware (n = 300)	35 (11.7%)	265 (88.3%)	**< 0.001**

Interpretation: Awareness of skin cancer risk was significantly associated with sunscreen usage ($p < 0.001$, Chi-square test).

5. Themes from Qualitative Analysis

Theme	**Key Illustrative Insights**
Cultural Myths & Social Stigma	"Many believe we are cursed; some even fear touching us."
Health System Discrimination	"Doctors avoid touching my skin… I felt humiliated."
Cost Barriers	"Sunscreen is too expensive. I have to choose between that and food."
Lack of Information	"No one told me I should go for skin checks… I thought the sores were just normal."
Survival Strategies	"I only go out early morning or late evening to avoid the sun."

Discussion

This study reveals a significant public health challenge facing persons with albinism (PWA) in Nigeria: **inadequate awareness of skin cancer risks** and **limited access to preventive and curative care**. Despite being among the most vulnerable populations to ultraviolet (UV) radiation due to lack of melanin, the findings show alarming gaps in both knowledge and support systems for PWA.

Low Awareness and Risk Perception

Although 68.7% of respondents had heard of skin cancer, only 36.7% were aware of its signs and symptoms, and fewer than half believed it was preventable with proper protection. These findings are consistent with studies in other sub-Saharan African countries, where persons with albinism often lack access to **accurate, culturally appropriate health information**. The low awareness significantly correlates with lower sunscreen usage rates, as confirmed by the statistically significant association ($p < 0.001$) found in this study.

Barriers to Protective Behavior

Only 24.7% of respondents regularly used sunscreen, and just 14.7% had ever undergone a skin check. These figures underscore **severe material and structural barriers** to preventive behavior. Qualitative accounts emphasized the unaffordability of sunscreen and lack of access to healthcare professionals knowledgeable about albinism-specific needs. Many participants described **resorting to limited sun exposure strategies** or using makeshift materials for protection.

Health System Discrimination

A striking 39.3% of respondents reported experiencing **discrimination in health facilities**, often manifesting as stigma, neglect, or a lack of understanding from healthcare providers. This institutional bias discourages help-seeking behavior and contributes to delayed diagnoses, as reflected in the 12.7% of respondents already diagnosed with pre-cancerous or cancerous lesions—likely an underestimate given the low skin check-up rates.

Geographical and Socioeconomic Disparities

Rural participants were particularly disadvantaged, with limited access to dermatologists, health education, and protective products. These findings reveal a **geographical inequity** in skin health resources, exacerbated by poverty and limited disability-inclusive policies in the healthcare system.

Cultural Myths and Stigma

The qualitative data revealed persistent **superstitions and myths about albinism**, such as beliefs that PWA are spiritually afflicted or untouchable. These cultural attitudes not only perpetuate social exclusion but also **deepen health disparities** by creating fear and misinformation around seeking care.

Strengths and Limitations

This study offers one of the most geographically representative datasets on PWA in Nigeria by combining quantitative and qualitative approaches. However, it relied on **self-reported data**, which may be subject to recall bias. Additionally, PWA outside of organized networks may have been underrepresented due to recruitment constraints.

Conclusion

This study highlights a profound public health and social equity issue affecting persons with albinism (PWA) in Nigeria. Despite their high vulnerability to skin cancer, the majority of PWA surveyed lacked adequate knowledge of risk factors, demonstrated limited engagement in preventive behaviors like sunscreen use, and reported significant barriers to accessing healthcare services. Systemic discrimination, poverty, and cultural stigma further compound these challenges.

The findings confirm that neglect—not biology alone—places PWA at higher risk for preventable conditions like skin cancer. Without deliberate policy intervention, this population will remain marginalized within Nigeria's healthcare framework, with long-term consequences for morbidity, mortality, and social inclusion.

Recommendations

1. Public Health Education Campaigns

4. Launch **targeted awareness campaigns** on skin cancer and albinism, especially in rural and underserved areas.

5. Collaborate with **albinism advocacy groups, religious leaders, and schools** to disseminate accurate, culturally sensitive information.

2. Subsidized Sun Protection Products

- Implement **government or NGO-supported distribution of sunscreens**, protective clothing, and wide-brim hats to PWA, especially in high-UV regions.

3. Training of Healthcare Providers

- Include **albinism-specific training** in the curricula of nurses, doctors, and community health workers to reduce stigma and improve quality of care.

4. Strengthen Health System Access

- Improve geographic and financial access by expanding **mobile dermatology clinics** and **community-based skin screening programs** in areas with large PWA populations.

5. Anti-Discrimination Legislation

6. Enforce and expand legal protections to **prevent discrimination** against persons with albinism in healthcare settings.

6. Further Research

3. Conduct **longitudinal studies** to assess trends in cancer prevalence, early detection, and healthcare utilization among PWA.

4. Explore **intersectional factors** (e.g., gender, rurality, education) that influence access and outcomes more deeply.

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