

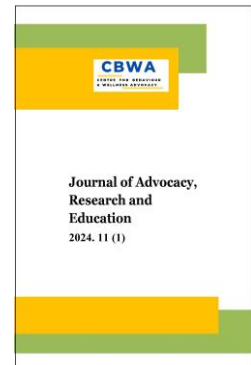


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Perceived Discrimination and Other Factors Influencing Self-Esteem in Persons with Albinism in North Central Nigeria

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Abstract

The deficiency of the photoprotective pigment in the skin of persons with albinism exposes them to various skin and eye disorders. Myths about persons with albinism have arisen from ignorance of their unique looks, which has also led to stigmatisation and discrimination of persons affected by the condition. These can affect individuals' self-esteem and may have long-term psychological and general well-being implications. A cross-sectional design was used to document the perceived discrimination against persons with albinism in the Plateau State of North Central Nigeria and examine the relationship with self-esteem levels. Participants (N = 42) completed the interviewer-based questionnaire centred on sources of support, avoidance, and abusive behaviour by others towards them. The Rosenberg self-esteem scale was used to estimate self-esteem, and information was analysed using SPSS version 26.0. The result showed more subjects were uncertain of fathers' acceptance than mothers (11.9 % vs 0.4 %), while 16 (38.1 %) were discriminated against by someone in a position of authority, 27 (64.3 %) had been verbally abused and 5 (9.5 %) physically abused on account of albinism. Challenges causing dissatisfaction were mainly financial, exposure to lack of protection from the sun and stigma. Self-esteem level was associated with the level of education, place of residence, the uncertainty of acceptance by the father, avoidance by peers, and being verbally abused. These findings serve as a baseline in advocating for policies to address stigma and discrimination against persons with albinism within communities while developing programs that aid in building their self-esteem.

Keywords: albino, self-confidence, stigma, acceptance, abuse, support, North Central Nigeria.

1. Introduction

Oculocutaneous albinism is an inherited disorder characterised by minimal or no melanin production, the photoprotective pigment that shields the skin from the damaging effects of the sun (Marcon, Maia, 2019). While persons with albinism are found in all races and cultures, the highest numbers are found in Africa, and most of those are believed to be in Nigeria, though no official data exists in regards to that (Ero et al., 2021; Hong et al., 2006; Lund et al., 1997; National Policy on Albinism, 2012). In addition to being noticeably paler than other members of the same race, as observed prominently in African albinos, the underlying melanin deficiency exposes the skin to the

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harmful effect of ultraviolet radiation from the sun. This results in an increased risk of developing a variety of solar-related skin disorders, even skin malignancies, from which a significant proportion have lost their lives (Awe, Azeke, 2018; Enitan et al., 2022; Lai et al., 2018). The condition also affects the eyes, resulting in decreased visual acuity, nystagmus, strabismus, and photophobia (Possi, Milinga, 2018).

Despite these physiological challenges, and perhaps because of them, misconceptions and myths have been spun around albinism, resulting in stigma and discrimination against persons with the condition. Many are denied access to social, economic, educational and health resources. Cases of injustice, bullying, physical abuse and being killed have been reported widely in this marginalised group in many developing countries (Ero et al., 2021; Hong et al., 2006; Possi, Milinga, 2018; Ikuomola, 2015; Ojilere, 2018; Aborisade, 2021). Since albinism is a lifelong disorder, these associated physiological, social, and economic challenges typically are ongoing.

Self-esteem is an individual's attitude toward oneself, whether favourable or negative (Rosenberg et al., 1995). The acceptance or rejection of others significantly impacts the development of self-esteem, which in turn impacts an individual's psychological, physical, social, and overall health at different stages of life. Low self-esteem has been shown to be intricately associated with low life satisfaction, antisocial behaviour, health-compromising behaviour, poor school performance and mental health disorders such as suicide ideation and depression (Berber, Odaci, 2020; Tus, 2020; Nguyen, 2019). Some of these have been reported in persons with albinism (Hong et al., 2006; Lund et al., 1997; Aborisade, 2021; Hajinia, Nasirian, 2014; Palmer, 2005; Ezeilo, 1989).

Much of the information on persons living with albinism in Nigeria has been on physical health and morbidity, with little on their psychological health. There is also very little information regarding abuse that individuals with albinism experience, particularly in the northern part of the country. The findings could be useful in advocacy, the development of policies, and interventions to achieve optimal well-being, given the negative effects abuse has on self-esteem. Therefore, this study aimed to assess and identify factors associated with self-esteem in Persons with Albinism in Plateau State, Northcentral Nigeria.

2. Materials and methods

Research design

The correlational research design was employed in this study as we sought to describe the relationship between self-esteem in Persons with Albinism and other variables.

Sampling

We used the convenience sampling strategy to recruit eligible subjects from persons with albinism from the different communities and local government of Plateau State who attended the health outreach organised in collaboration with the Centre for Albinism Right and Empowerment Network (CAREN), Plateau State, in January 2023. Participants under 12 years old and those who could not communicate in the English language or the commonly spoken 'broken English' were excluded.

Participants

Of the 81 persons with albinism who attended the outreach program, 42 of them aged 12 years and above were eligible and consented to be part of the study [N = 42] (male = 40.5 %; female 59.5 %).

Instrument for data collection

A semi-structured interviewer-administered questionnaire was designed to extract information from each respondent on socio-demographics, perceived abuse, source of support and how satisfied they were with the conditions they were currently in. The Rosenberg self-esteem scale developed in 1965 by Morris Rosenberg, designed for individuals ≥ 12 years of age, was another instrument adopted to estimate self-esteem by asking respondents to consider their current feelings in different areas (Berber, Odaci, 2020; Lima, Souza, 2019; García, 2019). The scale has an excellent internal consistency assessment on the Guttman scale coefficient of reproducibility of .92 and correlations as high as .85 and .88 in the test-retest reliability over two weeks. It also demonstrates a high level of validity (Rosenberg, 1979).

The ten statements of the scale had 4 Likert scale responses, which were strongly agree (4), agree (3), disagree (2) and strongly disagree (1) for the five positive worded statements. An example

of the positively worded statements is, “ I feel that I have a number of good qualities.” the five negatively worded ones, such as “At times, I think I am no good at all”, are scored in reverse. Higher total scores indicate higher levels of self-esteem; the range of total values obtainable is 10 to 40. Self-esteem was categorised as Low (10–25), which indicates feelings of incompetence, inadequacy, and difficulty in facing life’s challenges; Medium (26–29) suggests a fluctuation between feelings of approval and rejection; High self-esteem (30–40) indicates the individual is confident that they are valuable and competent (Lipenga, Ngwira, 2018).

Data collection

The data collection was guided by the ethical principles for research involving human subjects and complied with the Helsinki Declaration. Ethical approval was obtained from the Plateau State Ministry of Health Research and Ethical Committee [MOH/MIS/202/VOL2/X]. The purpose and methods of the study were explained to the eligible attendees, after which they were informed of the voluntary nature of participation and that refusal had no consequences. Consent was then obtained directly from the adult participants and the parents or guardians of participants under 18. In addition, assent was sought for those below 18 years. Information was collected using the questionnaire. Each questionnaire was checked for completeness and clarity before submission on-site.

Statistical analysis

Data collected were entered into and analysed with the Statistical Package for the Social Sciences (SPSS) version 26.0. Categorical variables such as gender and educational level are presented as frequency and percentages. Continuous variables like self-esteem scores were presented as mean and standard deviation and bivariate analysis was conducted using a t-test. The P value of < 0.05 is considered as significant.

3. Results

Table 1 showed that none of the participants were certain of their parents’ non-acceptance of them; however, a greater proportion were uncertain of fathers’ acceptance than mothers (11.9 % vs 0.4 %). The majority (64.3 %) were verbally abused on account of being persons with albinism, while only less than a tenth reported physical abuse for the same. A greater majority of respondents identified the family as the source of support, with no subject perceiving the government as supportive. Among those dissatisfied with their current state, financial issues were the most frequent reasons.

Table 1. Characteristics and perceptions of Persons with Albinism (N = 42)

S/N	Variables	Number (percentage)
1.	Age(years)	
	Range: 12-45 years	
	Mean: 24.57±9.22	
	Adolescents (12-19)	18(42.9)
	Adults (≥20)	24(47.1)
2.	Gender	
	male	17(40.5)
	female	25(59.5)
3.	Residential setting	
	Rural	14(33.3)
	Urban	28(66.7)
4.	Current level of Educational	
	None	4(9.5)
	primary	1(2.4)
	Secondary	22(52.4)
	Post-secondary	15(35.7)
5.	Family albinism	
	Yes	28(66.7)
	No	14(33.3)

S/N	Variables	Number (percentage)
6.	Father accepts me	
	Yes	37(88.1)
	Unsure	5(11.9)
7.	Mother accepts me	
	Yes	41(97.6)
	unsure	1(0.4)
8.	Discriminated against by authority figure (teacher, boss, health worker parent, traditional head)	
	Yes	16(38.1)
	No	26(61.9)
9.	Physical abuse on account of albinism	
	Yes	4(9.5)
	No	38(90.5)
10.	Verbal abuse on account of albinism (insults, name-calling, malicious teasing, jeering, cursing)	
	Yes	27(64.3)
	No	15(35.7)
	Verbal abused by Family member (5), known person (13), stranger/passersby (11) -multiple responses	
11.	Source of support (multiple response)	
	Family	38(90.5)
	Friends	9(21.4)
	School	10(23.8)
	Religious	8(19.0)
	Community	1(2.3)
	Non-Governmental Organization	6(14.3)
	Government	0(0.0)
	No support	4(9.5)
12.	Dissatisfied with the current state of life	
	Yes	23(54.8)
	No	19(45.2)
13.	Main reason underlying dissatisfaction	
	Financial (13)	
	Exposure and lack of protection to sunlight and elements (7)	
	Stigma (6)	
	Poor working/schooling conditions (4)	
	Don't know why (2)	
14.	I need a counsellor to improve my self-esteem	
	Yes	29(69.0)
	No	13(31.0)

The results in [Table 2](#) showed that two items, 'At times, I think I am no good at all' and 'I wish I could have more respect for myself', weighed below the weighted average (3.07) as large proportions of respondents (38.1 % and 97.6 %) agreed with the negatively worded statements. The range of total self-esteem scores was between 19 and 37, with a mean and standard deviation of 30.69 ± 5.12 . When categorised, 4 of 42 subjects (9.5 %) had low self-esteem, 16(38.1 %) had moderate self-esteem, and 22(52.4) had high self-esteem.

Table 2. Mean responses to Rosenberg Self-Esteem Scale items

Items	Strongly Agree n(%)	Agree n(%)	Disagree n(%)	Strongly Disagree n(%)	Mean±SD
Positively worded items					
1. On the whole, I am satisfied with myself	18(42.9)	20(47.6)	3(7.1)	1(2.1)	3.31±0.72
2. I have a number of good qualities.	15(35.7)	24(57.1)	3(7.1)	0(0)	3.29±0.59
3. I am able to do things as well as most other people	20(47.6)	16(38.1)	6(14.3)	0(0)	3.33±0.72
4. I'm a person of worth and equal to others.	19(45.2)	21(50.0)	2(4.8)	0(0)	3.40±0.59
5. I take a positive attitude toward myself.	17(40.5)	21(50.0)	4(9.5)	0(0)	3.31±0.64
Negatively worded items					
6. At times, I think I am no good at all.	1(2.4)	15(35.7)	12(28.6)	14(33.3)	2.93±0.89
7. I feel I do not have much to be proud of	2(4.8)	7(16.7)	17(40.5)	16(38.1)	3.12±0.86
8. I certainly feel useless at times.	2(4.8)	6(14.3)	18(42.9)	16(38.1)	3.14±0.84
9. I wish I could have more respect for myself.	20(47.6)	21(50.0)	1(2.4)	0(0)	1.55±0.55
10. All in all, I feel that I am a failure.	1(2.4)	4(9.5)	18(42.9)	19(45.2)	3.31±0.75

In [Table 3](#) above, the self-esteem of persons with albinism is shown to be significantly lower in the group who had no formal education and primary education than those with higher levels of education ($p=0.001$), in those living in rural areas than urban ($MD = 3.9$; $p = 0.045$), those uncertain of fathers' acceptance compared with those certain ($MD = 4.87$; $p = 0.038$). Self-esteem level was also noted to be lower among those who perceived that school or work colleagues avoided them ($MD = .468$; $p = 0.004$) and those who reported verbal abuse on account of albinism ($MD=3.70$; $p = 0.023$).

Table 3. Factors associated with self-esteem level of persons with albinism

S/N	Variable	Mean self-esteem score	Mean difference(MD)	t-test	p-value
1.	Age Adolescents Adults	32.06±3.8 29.67±5.78	2.40	1.52	0.14
2.	Gender Male Female	31.39±4.27 30.08±5.62	1.51	0.99	0.33
3.	Educational status † No formal education & primary	23.20± 7.73		8.25#	0.001

S/N	Variable	Mean self-esteem score	Mean difference(MD)	t-test	p-value
	Secondary	31.61±0.79			
	Post-secondary	31.86±4.00			
4.	Residence				
	Rural	28.50±6.63	3.29	2.03	0.045
	Urban	31.79±3.85			
5.	History of family albinism				
	Yes	29.96±5.44	2.18	1.31	0.20
	No	32.14±4.20			
6.	Father Accepts me				
	Yes	31.27±5.04	4.87	2.62	0.038
	uncertain	26.40±3.71			
7.	Discriminated against by someone in authority				
	Yes	29.88±5.49	1.32	0.77	0.45
	No	31.19±5.78			
8.	Colleagues avoid me				
	Yes	27.57±5.23	4.68	3.07	0.004
	No	32.25±4.36			
9.	Physical abuse on account of albinism				
	Yes	26.27±4.27	4.91	1.88	0.067
	No	31.16±			
10.	Verbal abuse on account of albinism				
	Yes	29.37±4.70	3.70	2.37	0.023
	No	33.07±5.12			
11.	Dissatisfied with the current state of life				
	Yes	30.91±5.59	0.49	0.31	0.76
	No	30.42±4.61			
12.	Needs counsel on self-esteem				
	Yes	30.93±4.79	0.79	0.29	0.76
	No	30.42±6.16			

Notes: †- Anova; # - F test

4. Discussion

Our study aimed to assess self-esteem levels and factors associated with the self-esteem of persons with albinism. The high mean scores obtained in individual items and summative scores of the Rosenberg self-esteem scale by most individuals indicate that most subjects perceived themselves as valuable and confident. This is a positive and commendable find, as skin colour has been found to affect self-esteem depending on whether it is perceived as atypical, as observed in albinism or a desired ideal with issues of colourism (Aborisade, 2021; Lipenga, Ngwira, 2018; Sharif, Siddique, 2020). Similar findings were reported in a previously conducted comparative study among secondary school students in South West Nigeria, where all subjects with albinism had moderate to high levels of self-esteem. In another study among teenagers with albinism in South Africa, significantly higher levels of self-esteem were observed compared to non-albino controls (Ahanonye, 2017; Selepe, 2007).

Our findings differ from that of a hospital-based study of persons with other skin conditions (acne, psoriasis and eczema) by Costeris (2021), showing significantly lower self-esteem and less social support they perceived they had compared with controls without these skin conditions. These may be coming from a sense of ill-health centred around these acquired conditions of hospital

subjects, which would explain the lower self-esteem compared to our finding of high self-esteem in persons with albinism. The person with albinism has a condition they were born with and have lived their entire life with, and they may also have psychologically adapted to it. Another possibility is that our participants' responses were influenced by being in a social gathering of individuals with albinism, which gave them a positive feeling during the interview, boosting their self-esteem.

Specific items (six and nine), which were negatively worded, had lower mean scores than other statement items. These statements were likely not understood due to cultural and language orientation differences. A statement such as, 'I wish I could have more respect for myself' may be answered with agreement regardless of how much respect they already had for themselves. In our setting, it may be understood as a positive statement. Furthermore, the larger proportion of our subjects with albinism had educational levels above the primary level as opposed to reports from previous studies of a significant proportion of persons in this marginalised group having little or no formal education (Ero et al., 2021; Hong et al., 2006; Possi, Milinga, 2018). This may mean more persons affected by albinism are no longer being restricted to the home as it was in the past but are out accessing educational institutions, which underscores the need for low vision aids and skin protective strategies.

The difference we found in self-esteem levels between the education levels was expected as self-efficacy, which is usually higher with higher levels of education is a component of self-esteem. Self-esteem, in turn, is a driver in pursuing and completing educational goals; implying that inculcating educational interventions for this disadvantaged group is crucial (Bano et al., 2015; Ferkany, 2008). Also, being a resident of an urban area increases access to education, health, and other social infrastructure and will likely affect self-esteem positively. This explains the relationship between place of residence and self-esteem levels found in our study participants.

Compared to mothers, a larger number of participants expressed uncertainty about their fathers' acceptance of them, and those who were uncertain of their fathers' support also showed significantly lower levels of self-esteem. Fathers are more reluctant to accept infants with albinism and, in some cases, reject both mother and child (Ero et al., 2021; Kromberg, 2018; Lipenga, Nwigira, 2018). Fathers' acceptance and support are so crucial that they have been shown to be a major contributor to building self-esteem and psychological adjustment in childhood and even up to adulthood (Wagani, 2016). This has also been noted specifically among persons with albinism (Ero et al., 2021; Hajinia, Nasirian, 2014).

Furthermore, discrimination against individuals with albinism by persons in place of authority was common among the study's participants, with more than a third reporting such experiences. This is consistent with others who reported prevalent institutional, family, and community abuse and prejudice (Ero et al., 2021; Hong et al., 2006). There was no significant difference in self-esteem levels compared to individuals who had not reported discrimination. This could be due to the commonplace abuse by authority figures across the country, regardless of a person's disability status (Etieyibo, Omiegbe, 2016; Ojilere, 2018). On the other hand, being avoided by colleagues at work or school and being verbally abused were associated with lower self-esteem scores. These are expressions and effects of the relatively common stigma caused by ignorance, resulting in the stigmatised groups losing status in different aspects, including economically, socially, and politically (Aborisade, 2021; Ikuomola, 2015; Lin 2020 et al., 2020). Physical abuse was less common than others reported. However, the participants may not have linked any physical abuse they experienced to albinism; it is not clear if this is reflective of the situation on the Plateau.

The sense of dissatisfaction experienced by over half of our subjects did not influence self-esteem levels and was mainly attributed to challenges with finance, exposure to the sun and stigma, which encapsulates the most fundamental and urgent needs of persons with albinism across Africa. Having family as the primary source of support with little or no institutional support for the unique needs of individuals with albinism may lead to a lot of strain on the already limited resources, resulting in neglect and worsening of the psychology and physical morbidities.

5. Limitation

Our findings may not be generalisable due to the convenience sampling of individuals with albinism whom the organisation could reach. Research conducted on neglected persons or those from remote and difficult-to-reach areas who were not invited may have revealed different outcomes.

6. Implications of the study

In this study, our primary goal was to evaluate persons with albinism's self-esteem levels and related factors, especially discrimination by others. We have done this by documenting discriminatory behaviours and attitudes that persons with albinism have encountered from various sources. This has implications for the prevalent beliefs and practices in a community that may be harmful to disadvantaged individuals in general and to people with albinism in particular. Another implication is that in addition to physical health, there is a need to prioritise the psychological health of individuals and groups with albinism. Providing these vulnerable persons in Nigeria with visual aids and skin protective commodities will likely reduce dissatisfaction and improve self-esteem and overall health.

7. Conclusion

The findings of this study have indicated that even though persons with albinism are exposed to different forms of prejudice, a large proportion of them still have high self-esteem. Self-esteem is negatively influenced by lower educational level, residing in rural areas, uncertainty of acceptance by father, being avoided by peers and verbal abuse—a follow-up to trace and explore the state of persons with albinism, even in remote rural settlements. Institutional support is needed to provide basic amenities, education and healthcare. This support will help boost the self-esteem and overall health of persons with albinism. To combat stigmatisation and discrimination, a continuous awareness programme targeted at family members and community members of persons with albinism is required.

8. Declarations

Data collection was guided by ethical principles for research involving human subjects and complied with the Helsinki Declaration. Ethical approval was obtained from the Plateau State Ministry of Health Research and Ethical Committee (MOH/MIS/202/VOL2/X). Informed consent was obtained with assurance that declining to partake had no negative consequences.

Consent for publication

Not applicable

Availability of data and materials

Data and other related study materials are available upon request.

Conflict of interest

The authors have no conflict of interest to disclose, and all reference materials have been duly acknowledged.


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