



Research Paper

IMPACT OF VISUAL IMPAIRMENT ON THE QUALITY OF LIFE AMONG PERSONS WITH ALBINISM IN A SOUTHERN NIGERIAN CITY

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Abstract

Aim: To determine the impact of visual impairment on the quality of life among 'Persons with Albinism' (PWA) in Port Harcourt, Southern Nigeria.

Method: A descriptive cross-sectional study of 116 persons with albinism in Port Harcourt, assessed within a period of 5 months. The participants' visual acuity, level of visual impairment determined from the WHO classification of Visual impairment and quality of life measured with National Eye Institute Visual Functional Questionnaire 25 (NEIVFQ-25) for participants above 18 years old and the Children's Visual Function Questionnaire (CVFQ) for participants below 18 years old. Detailed ocular examinations, visual acuity, anterior and posterior segments were carried out. Data was analyzed using SPSS version 25. Chi square and Independent sample T test were the statistical tools employed in comparison of variables as appropriate. A p-value ≤ 0.05 was considered statistically significant. **Results:** Over seventy-four percent of the eyes examined had moderate visual impairment for distance and sixty-nine percent had moderate visual impairment for near. After refraction and subjective corrections, the number of eyes with normal vision increased from 4 (1.7%) eyes to 20 (8.6%) eyes for distance vision and from 8 (3.4%) eyes to 60 (25.9%) eyes for near vision; while the number of blind eyes reduced from 24 (10.4%) to 8 (3.4%). There was a decline in the quality of life proportionate to the severity of visual impairment. **Conclusion:** There was a steady decline in the in the quality of life among the adults and children proportionate with the severity of visual impairment.

Key words: Visual impairment, Quality of life, Persons with albinism.

INTRODUCTION

Albinism is a hereditary condition characterized by a decrease or absence of pigment in the hair, eyes and skin of affected individuals resulting from disruption in melanin

pigment synthesis as a result of mutations in various enzymes and membrane proteins [1]. Albinism could be Oculocutaneous albinism (OCA) and Ocular albinism (OA). In Oculocutaneous albinism, the hair, skin and eyes are affected while in Ocular albinism the features may be confined to the eyes and visual system [2].

Disruption in melanin synthesis has been proven to result in severe abnormality in the development of the visual system leading to several visual deficits including delayed visual maturation, nystagmus, iris trans-illumination, strabismus, impaired color vision, visual impairment and reduced contrast sensitivity and stereoacuity, optic nerve hypoplasia, abnormal fovea and abnormal decussation of the optic chiasm [3,4,5].

In Nigeria, it has been established that majority of patients with albinism have subnormal distance and near visual acuity and this is said to have a serious impact on the learning ability of children and activities of daily living of adults [6,7,8]. Therefore current information about prevalence is essential in resource allocation and planning of prevention strategies in line with World Health Organization's (WHO) global target to reduce the prevalence of avoidable visual impairment by 25% by 2019 from the baseline of 2010 [9].

In Nigeria, a multitude of challenges - psychological, social, educational or health-related (skin cancer, severe visual impairment) still besiege persons living with albinism [7,10]. In addition to the clinical evaluation of visual function of PWA, it is therefore important to also understand the effect of the visual challenges in the quality of life of these unique group in our society. Various researchers have identified difficulty in reading printed materials, difficulty driving vehicles, poor performing of tasks at home, glare and problem recognizing faces as some of the challenges of PWA [11,12]. Felius et al in a study of 91 children with albinism reported that binocular visual impairment was associated with a reduction in the vision related quality of life [13]. Using National Eye Institute Visual Functional Questionnaire 25 (NEIVFQ-25), Kutzbach et al in Minnesota observed that persons aged 18 years and older had lower quality of life as compared with their normal counterparts [14,15]. In Enugu, Attama et al utilized a non-vision specific psychometric instrument (WHO Quality of Life-Bref) and observed that there was a deficit in the quality of life of persons with albinism [6].

This study aims to determine the impact of visual impairment on the quality of life among 'Persons with Albinism' (PWA) in Port Harcourt, Southern Nigeria.

MATERIALS AND METHODS

This was a descriptive cross-sectional study of 116 persons (232 eyes) with albinism (PWA) recruited from The Albinism Foundation in Port Harcourt City, Rivers State, Nigeria over a five-month period (from November 2016 to March 2017).

A semi-structured pretested questionnaire was used to record age, gender, relevant ocular and medical history, visual acuity and clinical examination findings. Subjective and objective visual assessments were used to ascertain the participants visual acuity, visual needs and challenges. Distance visual acuity was assessed using the Early Treatment Diabetic Retinopathy Study (ETDRS) chart placed at 4metres under standard illumination and recorded in Logarithm of the Minimum Angle of Resolution (logMAR) units while the near acuity was assessed using Radner Reading Chart at 40cm.

The participants' visual acuity, level of visual impairment determined from the WHO classification of Visual impairment [6,16]. Quality of Life was measured with National Eye Institute Visual Functional Questionnaire 25 (NEIVFQ-25) for participants above 18 years old and the Children's Visual Function Questionnaire (CVFQ) for participants below 18 years old [15,17].

Data obtained was analyzed using the Statistical Package for Social Sciences (SPSS version 25, SPSS Inc., IBM, USA). Simple statistics such as means and frequencies were determined. Independent sample T test and the Chi square test used to compare the appropriate variables. A p-value ≤ 0.05 was considered statistically significant.

RESULTS

Table 1: Age and Gender Distribution of Study Subjects

Age Groups (Years)	Male (n) (%)		Gender Female (n) (%)		TOTAL (%)	
	Male		Female		Total	
	Number (%)		Number (%)		Number (%)	
< 10	10	(8.6)	12	(10.3)	22	(19)
11-20	8	(6.9)	16	(13.8)	24	(20.7)
21-30	8	(6.9)	14	(12.1)	22	(19)
31-40	14		16	(13.8)	30	(25.9)
41-50	2	(1.7)	12	(10.3)	14	(12.1)
51 and above	2	(1.7)	2	(1.7)	4	(3.4)
Total	44	(37.9)	72	(62.1)	116	(100.0)

There were 44 (37.9%) males and 72 (62.1%) females with a male to female ratio of 1:1.6. The mean age of participants was 26.1 ± 14.3 . Age range was 5 to 56 years. The modal age group was 31- 40 years and accounted for 25.9 % of the study participants.

Table 2: Socio-Demographic Characteristics of PWA

Occupation	Educational status No. (%)			Total	Chi square (p value)
	Primary	Secondary	Tertiary		
Student	24 (20.7)	12 (10.3)	8 (6.9)	44 (37.9)	35.94 (*0.001)
Unemployed	2 (1.7)	22 (19.0)	2 (1.7)	26 (22.4)	
Artisan	0 (0.0)	2 (1.7)	0 (0.0)	2 (1.7)	
Apprentice	0 (0.0)	2 (1.7)	0 (0.0)	2 (1.7)	
Business owner	2 (1.7)	14 (12.1)	2 (1.7)	18 (15.5)	
Civil servant	0 (0.0)	6 (5.2)	8 (6.9)	14 (12.1)	
Professional career	0 (0.0)	0 (0.0)	10 (8.6)	10 (8.6)	
Total	28 (24.1)	58 (50.0)	30 (25.9)	116 (100.0)	

Fifty percent of the study participants had secondary education. Most participants were either students (n= 44, 37.9%) or unemployed (n= 26; 22.4%); this was statistically significant (p=0.001).

Table 3: Mean Quality of Life Person Scores in the Study Population

QoL Scores	No.	Range		Mean ± SD
		Minimum	Maximum	
LVP FVQ II				
Composite raw person score	38	28.00	63.00	45.26 ± 9.71
NEIVFQ-25 Items				
Colour vision	78	25.00	100.00	86.53± 21.34
Social functioning	78	25.00	100.00	74.03± 25.06
General vision	78	20.00	100.00	66.15± 18.44
General health	78	25.00	100.00	60.89±23.50
Ocular pain	78	12.50	100.00	60.58±23.74
Dependency	78	0.00	100.00	57.90±32.55
Peripheral vision	78	0.00	100.00	56.41± 28.51
Near activities	78	16.66	100.00	54.69±22.84
Distance activities	78	8.33	91.66	52.77± 23.20
Role difficulties	78	12.50	100.00	51.28±21.61
Mental health	78	6.25	100.00	46.63± 27.61
Driving	16	0.00	83.33	39.58±37.20
Composite person score	78	19.29	92.80	60.09± 17.07

LVP-FVQ II: Least ability/ most difficult=23, Highest ability/ least difficult=69

NEIVFQ Subscale items are arranged in hierarchy from least difficult to most difficult task. Most difficult/ least ability=0, Least difficult/ highest ability=100

The mean quality of life scores derived from the age appropriate psychometric instruments used; the LVP FVQ II composite person raw score of the participants ranged from 28 to 63 with a mean score of 45.26 ± 9.71 while NEIVFQ-25 composite score ranged from 19.29 to 92.80 with a mean value of 60.09 ± 17.07. The NEIVFQ-25 subscale with the lowest mean score of 39.58 ± 37.2 and therefore the most difficult was driving followed by mental health with a mean score of 46.63 ± 27.61. The least difficult subscale was color vision with a mean score of 86.53 ± 21.34.

Table 4: Distribution of NEIVFQ-25 Subscale scores (Quality of Life) in the 78 adult participants

NEIVFQ-25 Subscales	Quality of Life Score Categories				
	Number of Participants (%)				
	Group 1 (QoL ≤ 25)	Group 2 (QoL 26-50)	Group 3 (QoL 51-75)	Group 4 (QoL >75)	Total Participants
Colour vision	4 (5.1)	6 (7.7)	18 (23.1)	50 (64.1)	78 (100)
Social functioning	10 (12.8)	6 (7.7)	26 (33.3)	36 (46.2)	78(100)
General vision	2 (2.6)	10 (12.8)	36 (46.2)	30 (38.5)	78(100)
General health	14 (17.9)	26 (33.3)	28 (35.9)	10 (12.8)	78(100)
Ocular pain	6 (7.7)	34 (43.6)	24 (30.8)	14 (17.9)	78(100)
Dependency	18 (23.1)	22 (28.2)	10 (12.8)	28 (35.9)	78(100)
Peripheral vision	24 (30.8)	22 (28.2)	18 (23.1)	14 (17.9)	78(100)
Near activities	16 (20.5)	20 (25.6)	30 (38.5)	12 (15.4)	78(100)
Distance activities	14 (17.9)	28 (35.9)	24 (30.8)	12 (15.4)	78(100)
Role difficulties	16 (20.5)	36 (46.2)	18 (23.1)	8 (10.3)	78(100)
Mental health	24 (30.8)	26 (33.3)	10 (12.8)	18 (23.1)	78(100)
Driving	8 (50.0)	0 (0.0)	6 (37.5)	2 (12.5)	16(100)
Composite person score	2 (2.6)	18 (23.1)	34 (43.6)	24 (30.8)	78(100)

Legend: QoL-Quality of Life. Group 1-least functional ability, Group 4- highest functional ability

Table 4 shows the distribution of adult participants among 4 category groups of QoL scores from the lowest functional category of ≤ 25 (Group 1) to the highest functional group of >75 (Group 4). Most of the participants self-reported that they had good functional ability in activities involving color vision (n=50; 64.1%) and social activities (n=36; 46.2%). The subscale with the highest number of participants with the least functional ability (Group 1) was driving (n=8/16, 50%). Most of the participants reported a fair functional ability (Group 2) with activities related to mental health (n=26, 33.3%), role difficulties (n=36, 46.2%), distance activities (n=28, 35.9%) and ocular pain (n=34, 43.6%). Overall, the composite score indicated that most participants (n=34; 43.6%) self-reported that they had a moderate functional ability.

Table 5: Quality of Life scores and Mean Presenting Visual Acuity in the Better Eye

Visual Acuity Categories	QoL Composite Score Mean \pm SD			
Better eye	LVP FVQ II (<18 years)	NEIVFQ	25	(\geq 18years)
Normal vision (\geq 0.3; 6/12)	-	92.80 \pm 0.00		
Mild VI (< 0.3 - \geq 0.48; 6/12- 6/18)	59.00 \pm 6.92	-		
Moderate VI (<0.48 - \geq 1.0; 6/18- 6/60)	42.73 \pm 8.15	60.63 \pm 15.04		
Severe VI (<1.0 - \geq 1.3; 6/60- 3/60)	42.00 \pm 0.00	56.87 \pm 17.95		
Blindness (<1.3 - \geq 2.0; 3/60- NLP)	-	52.20 \pm 24.79		
	F test (p 5.241 (*0.018)	1.715 (0.182)		
	value)			

Legend: QoL- Quality of Life, VI- Visual impairment. *p value is statistically significant

The LVP-FVQ II composite scores in children significantly ($p=0.018$) reduced from 59.00 \pm 6.92 in those with mild visual impairment to 42.00 in those with severe visual impairment. The NEIVFQ 25 composite scores also showed a steady decline in the quality of life amongst adults as a reduction was noted in the composite score of those with visual impairment or blindness (score=52.20 \pm 24.79) compared to those with normal vision (score=92.80). However, this decline in NEIVFQ QoL score was not statistically significant ($p=0.182$). No child was also blind and none had normal vision.

All the measures of visual function had a weak correlation with general health, ocular pain, social functioning, role difficulty, peripheral and color vision subscales. Of all the visual function measures, contrast sensitivity of the better eye had the highest and most statistically significant association with general vision ($R_s=0.36$, $p=0.022$), near activities ($R_s =0.38$, $p=0.018$) and distance activities ($R_s =0.42$, $p=0.008$). Mental health had a significant association with near acuity of the better ($R_s =0.36$, $p=0.026$) and worse eye ($R_s =0.33$, $p=0.044$). Driving was the only subscale that had a strong significant correlation with near acuity of the better ($R_s =0.75$, $p=0.031$) and worse eye ($R_s =0.79$, $p=0.019$) and contrast sensitivity of the better eye ($R_s =0.73$, $p=0.038$).

Table 6: Relationship between Visual Function and NEIVFQ-25 Subscales in the Better and Worse Eyes.

NEIVFQ Subscales	Distance Acuity Rs (p value)		Near Acuity Rs (p value)		Contrast Sensitivity Rs (p value)	
	Better Eye	Worse Eye	Better Eye	Worse Eye	Better Eye	Worse Eye
General Health	-0.16 (0.34)	-0.17 (0.297)	-	-0.26 (0.10)	0.17 (0.30)	0.18 (0.27)
General Vision	-0.23 (0.15)	-0.33 (*0.043)	-0.29 (0.07)	-0.33 (*0.043)	0.36 (*0.022)	0.35 (*0.029)
Ocular Pain	-0.062 (0.71)	-0.15 (0.34)	-0.13 (0.41)	-0.11 (0.50)	0.12 (0.447)	0.09 (0.55)
Near Activities	-0.33 (*0.042)	-0.33 (*0.042)	-0.30 (0.06)	-0.34 (*0.034)	0.38 (*0.018)	0.29 (0.07)
Distance Activities	-0.37 (*0.022)	-0.40 (*0.011)	-0.31 (0.053)	-0.33 (*0.039)	0.42 (*0.008)	0.33 (*0.039)
Social Function	-0.084 (0.61)	-	-0.12 (0.46)	-0.20 (0.20)	0.14 (0.401)	0.24 (0.135)
Mental Health	-0.24 (0.12)	-0.31 (0.054)	-0.36 (*0.026)	-0.33 (*0.044)	0.29 (0.069)	0.27 (0.08)
Role Difficulties	-0.13 (0.40)	-0.10 (0.54)	-0.02 (0.89)	-0.09 (0.57)	0.22 (0.174)	0.18 (0.26)
Dependency	-0.29 (0.071)	-0.35 (*0.028)	-0.27 (0.09)	-0.38 (*0.016)	0.32 (*0.048)	0.30 (0.061)
Driving	-0.58 (0.126)	-0.59 (0.126)	-0.75 (*0.031)	-0.79 (*0.019)	0.73 (*0.038)	0.56 (0.14)
Peripheral Vision	-0.062 (0.70)	-0.14 (0.40)	-0.16 (0.33)	-0.16 (0.33)	0.22 (0.176)	0.11 (0.49)
Colour Vision	-0.105 (0.52)	-0.07 (0.64)	-0.06 (0.71)	-0.15 (0.34)	0.12 (0.466)	0.19 (0.23)

Legend: Rs- Spearman correlation rho value of <0.30 shows a weak correlation, 0.30 to 0.49 shows a moderate correlation while ≥ 0.50 indicates a strong correlation

DISCUSSION

People living with albinism in Nigeria have various visual challenges that affect their activities of daily living and also compromise their level of social engagement. This study evaluates the impact of visual impairment on the quality of life among 116 persons 'Persons with Albinism' (PWA) in Port Harcourt, Southern Nigeria.

Socio-Demographic Characteristics

There were 44 (37.9%) males and 72 (62.1%) females with a male to female ratio of 1:1.6. The mean age of participants was 26.1 ± 14.3 ; with age range of 5 to 56 years. The modal age group was 31- 40 years and accounted for 25.9 % of the study participants.

This is similar to at the findings of researchers in other regions of Nigeria [10,18,19]. Studies by Khanal et al in Nepal and Eballe et al in Cameroun reported mean ages similar to this study while a higher mean age of 42 years was reported in the United Kingdom [20,21,22]. Perhaps the observed difference could be due to variations in the living standard and better health care system in the United Kingdom.

Over 60% of the study participants were either students or unemployed. Fifty percent of the participants had secondary education (n=58; 50.0%) but out of these, 39.7% (n=46) were secondary school dropouts. The number of drop out from educational institution was statistically significant ($p=0.001$). This is in contrast to an earlier study in Enugu, South East Nigeria where more than half of the participants had tertiary education [18]. The reason for this difference could be because The Albinism Foundation (TAF), Enugu chapter has been in existence earlier than the Port Harcourt branch hence its members have better access to spectacles, low vision aids and other social benefits from the support group which in turn might have encouraged them to continue their educational pursuits. The recent rise in cost of tertiary education and the financial burden of purchasing low vision aids also make it more frustrating for a PWA to continue with education. Stigmatization, visual impairment and physical appearance all play a major role in the high unemployment rate and the poor or lack of social interaction. In this respect, females are more vulnerable as they may not meet the societal norm for marriage in a male-dominated society where it is always the man who seeks out a wife. This may explain the female preponderance in this study population. Therefore, increase in public funding and social awareness is needed so as to maximize the potentials of a PWA and hence improve employable skills.

Quality of life

Most participants in this study had low quality of life. Using the NEIVFQ-25 subscale [15], the lowest mean score was 39.58 ± 37.2 (Table 3). The most difficult task to execute by majority of the study subjects was driving. Mental health had a mean score of 46.63 ± 27.61 . The least difficult subscale was color vision with a mean score of 86.53 ± 21.34 .

This is not surprising as activities associated with contrast sensitivity such as driving at night or in the rain and navigation in unfamiliar surroundings (during business activities) are commonly undertaken by adults. Similar findings of impaired mean

contrast sensitivity was noted in South Africa, Chicago, Malawi and Egypt [23,24,25,26]. Factors thought to be responsible for the degradation in contrast sensitivity include increased central retinal cone spacing, abnormal decussation of the visual pathway and glare from iris hypopigmentation, nystagmus and foveal hypoplasia.

In the ophthalmic management of PWA, the end goal is to improve or preserve vision and therefore their quality of life. Using age appropriate vision-related quality of life instruments, this study examined the various visual challenges PWA face on a daily basis and how they affect their quality of life. To the best of the author's knowledge, this study is the first to use LV Prasad FVQ-II to assess functional vision in Nigerian children with albinism. The most difficult task was copying letters from the blackboard, reading the tiny print on biscuit packs and threading a needle. Other studies that used LVPFVQ-I to assess functional vision in children with visual impairment had similar results [26,27]. This implies that children with albinism experienced difficulty in performing tasks related to vision both at home and in school. In comparing their vision to those of normal sighted friends, most participants reported that their vision was worse.

Relationship between Visual Function and QoL

There was a strong significant correlation between LVP-FVQ score and visual acuity in the better eye, worse eye and both eyes was found. The only significant association with contrast sensitivity was when the test was done binocularly. Gothwal et al used the same questionnaire in India and observed similar result - a moderate significant association between binocular visual acuity, contrast sensitivity and quality of life [28].

LVP-FVQ raw person score in the participants reflected overall poor level of functioning. The composite raw person score in those with mild visual impairment was significantly higher than those with severe visual impairment ($p=0.018$). LVP-FVQ score was significantly lower in the presence of nystagmus but had no significant association with iris trans-illumination. The reason for this is that glare sensitivity from iris trans-illumination is known to affect adults more often than children while nystagmus is worse in childhood. Overall, the results indicate that with deterioration of visual acuity, presence of nystagmus and to a lesser extent impaired contrast sensitivity, there is a corresponding worsening of QoL in children with albinism. Felius et al in the USA using a different instrument (Children Visual Function Questionnaire-CVFQ) also observed a

reduction in mean QoL score that had a significant relationship with visual acuity [13,17]. This indicates that impaired visual function affects quality of life of PWA irrespective of the geographical location and socioeconomic status.

CONCLUSION

There was a steady decline in the in the quality of life among PWA proportionate with the severity of visual impairment. The benefits and privileges of affected families joining a support group such as The Albino Foundation (TAF) cannot be overemphasized as they help in educating and promoting healthcare and social acceptance for PWA, assist in soliciting government intervention and also increase awareness about on-going clinical trials for albinism treatment.

CONSENT AND ETHICAL APPROVAL

As per university standard guideline participant consent and ethical approval has been collected and preserved by the authors.

COMPETING INTERESTS

Authors have declared that no competing interests exist.

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