



## Quality of Life of Subjects with Leprosy and Albinism

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### Authors' contributions

*This work was carried out in collaboration between all authors. Author CMA designed the study and wrote the protocol. Authors MNI and NOO performed the statistical analysis, managed the literature search and wrote the first draft of the manuscript with assistance from author EOO. All authors read and approved the final manuscript.*

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### ABSTRACT

**Background:** Disfiguring skin disorders like leprosy and albinism may negatively distort a patient's body image with resultant impairment in quality of life.

**Objective:** This study determined and compared the quality of life (QoL) of subjects with leprosy and those with albinism.

**Methods:** Two hundred subjects were recruited from a Leprosarium and The Albino Foundation in South East Nigeria. The participants were interviewed with Socio-demographic Interview Schedule and WHOQoL-Bref.

**Results:** Subjects with leprosy had lower QoL scores compared with subjects who have albinism in all domains. Male and female subjects with leprosy scored lower in all domains than male ( $p = 0.02$ ) and female ( $p = 0.04$ ) subjects with albinism. Married subjects with leprosy scored lower than

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married subjects with albinism in environment domain only ( $p= 0.04$ ). Unmarried subjects with leprosy had lower QoL scores in the social relationship and environment domains ( $p = 0.01$ ). Employed and unemployed subjects with leprosy scored lower than employed ( $p = 0.01$ ) and unemployed ( $p = 0.03$ ) subjects with albinism in all domains. Educated and uneducated subjects with leprosy scored lower than educated ( $p = 0.02$ ) and uneducated ( $p = 0.03$ ) subjects with albinism in all domains.

**Conclusion:** Impairment in QoL was greater in subjects with leprosy compared to those with albinism.

*Keywords: Quality of life; leprosy; albinism.*

## 1. INTRODUCTION

Skin, being the largest organ in the body, carries immense psychological significance. It is not only an organ of temperature, touch and pain, but also an organ of emotional expression, and site for discharge of anxiety [1]. Leprosy is a chronic infectious disease of the skin. People affected by the disorder have been stigmatized since ancient times till now. This has caused difficulties in the lives of those affected [2]. This stigmatization also applies to albinism [3].

Leprosy with its associated stigma has pervading effects on many aspects of a patient's life [4]. This includes quality of life. Geetha and Sundra [5], in India, reported the mean quality of life score of subjects with leprosy as lower than that of patients with other skin diseases. That study also reported that women had higher quality of life scores than men. The deformities that arise from leprosy may lead victims to lose jobs and income [6]. The physical deformities in subjects with leprosy make them accept reduction in pay, while some of them resort to begging [7,8]. The salary reduction and loss of their sources of income affect their quality of life adversely [7]. Lower income has been reported to adversely affect quality of life [9]. Atsuro et al. [10] studied 189 patients with leprosy and 200 people without leprosy in Italy, reported that fewer years of education, presence of deformities and lower annual income were associated with low quality of life. Costa et al. [11] in Brazil carried out a cross sectional study on 120 subjects with leprosy being treated for leprosy reactional states. They found that lowest QoL was observed in the physical domain while highest QoL was observed in the psychological and social relations. Some traditions disallow marriages to subjects with leprosy. According to Mugenya [12], in some parts of Kenya, there are very strict rules against subjects with leprosy when marriage issues are concerned. Han et al. [13] reported that there was significant

relationship between marital status and QoL, and this relationship appeared to differ by gender and age.

Esther et al. [14] also reported that most people in Africa with albinism were generally reported to be of low economic status in their society. A cross-sectional study involving 1000 subjects with albinism in Nigeria, reported that ocular defects retarded the progress of many subjects with albinism in school and they eventually dropped out to seek menial occupation. This reduced chance of being involved in higher occupation may eventually lead to impairment in their quality of life [3]. A study in Tanzania involving 149 subjects with albinism reported that 46.6% were discriminated against during employment. This discrimination in employment affected their quality of life adversely [15]. In Tanzania, majority of subjects with albinism showed signs of sun damage to their skin within 10 years of life and by 20-30 years, half will have advanced skin cancers [16]. Living with cancer affects quality of life adversely [17]. Furthermore in Tanzania, albinos are subjects of brutal hunt by sorcerers who murder them for their body parts, believing that such parts cure AIDS. Between 2007 and 2008, about 70 subjects with albinism were killed by albino hunters within a region. In order to avoid being killed, they were sheltered at a refugee camp with armed police protection. Living in sheltered refugee camps robbed them of the opportunity to fend for themselves thereby impairing their quality of life [15].

Impaired quality of life may have adverse effects on the health of subjects with leprosy and subjects with albinism. Yet, this is not often assessed routinely in clinical practice. This study is designed to contribute in this area.

## 2. STUDY DESIGN

This study was a comparative cross-sectional study of subjects with leprosy at Mile Four

Specialist Hospital (Catholic Mission Hospital) Abakaliki, Ebonyi State and subjects with albinism at Enugu City, Enugu State, Nigeria.

## 2.1 Ethical Issues

Permission to conduct this study was obtained from the Institutional Review Boards of Mile Four Specialist Hospital and The Albino Foundation.

## 2.2 Participants

Two hundred participants were interviewed. One hundred subjects diagnosed of leprosy by a dermatologist were initially recruited. Another one hundred subjects with albinism at The Albino Foundation in Enugu City, Enugu State were also recruited. Only adults aged 18-64 years were interviewed. Those excluded from the study included subjects with co-morbid albinism and leprosy, learning disability, or objection to giving informed consent.

## 2.3 Instruments for the Study

### 2.3.1 The socio-demographic interview schedule

Demographic information was obtained using a standard socio-demographic interview schedule. The following demographic details were obtained- age, sex, marital status, occupation, highest level of education, ethnic background and religion.

### 2.3.2 The World Health Organization Quality of Life-Bref (WHOQoL-Bref)

This is a 26-item questionnaire, being a shorter version of the original WHOQoL-100 scale. It is more convenient for use in large research studies or clinical trials [18]. This instrument emphasizes the subjective responses of subjects rather than the objective conditions. It enables health professionals to assess changes over the course of treatment. It is anticipated that, in the future, the WHOQoL-Bref will be useful in health policy research and will make up an important aspect of the routine auditing of health and social services [19]. There are also two items that are examined separately: Question 1 asks about an individual's overall perception of quality of life and question 2 asks about an individual's overall perception of their health. The remaining 24 items ask about the 4 domains; physical,

psychological, social relationship and environment domains.

## 2.4 Sample Selection and Procedure

Subjects were selected using the systematic random sampling method. Socio-demographic Interview Schedule and WHOQoL-Bref were subsequently used to interview them. Recruitment was over 16 week period and adequate precautions were taken to avoid interviewing a participant twice.

## 2.5 Statistical Analysis

The Statistical Package for Social Sciences (SPSS) version 16.0 was used for analysis. Basic descriptive statistics was used to present the socio-demographic profile of the subjects. Student t-test and Chi-square test were also used where applicable. All tests of significance were at 5% level of significance ( $p < 0.05$ ) and confidence interval estimation of 95%.

## 3. RESULTS

### 3.1 Demographic Information

The subjects with albinism were younger with mean age of  $36.6 \pm 12.7$  years than subjects with leprosy who had mean age of  $43.23 \pm 16.9$  years ( $t=3.08$ ,  $p=0.02$ ). One hundred (100%) subjects with leprosy were of Igbo ethnic group. Ninety nine (99%) subjects with albinism were of Igbo ethnic group while only 1(1%) was of Yoruba ethnic group. Female subjects with albinism were 63 (63%) whereas among the subjects with leprosy 43 (43%) were female ( $\chi^2=8.03$ ,  $p=0.04$ ). Married subjects with leprosy were 66 (66%) compared to 28 (28%) of subjects with albinism ( $\chi^2=35.71$ ,  $p < 0.001$ ). Educated subjects with albinism were 86 (86%) while 58 (58%) of subjects with leprosy were educated ( $\chi^2= 96.68$ ,  $p < 0.001$ ). One hundred (100%) subjects with albinism were Christians, while 89 (89%) subjects with leprosy were Christians. Eleven (11%) of the subjects with leprosy belonged to African traditional religion ( $\chi^2= 11.64$ ,  $p=0.03$ ). The subjects with albinism had more professionals, or those in semi-skilled occupation than the subjects with leprosy (MW-u=1702.0,  $p < 0.001$ ). Subjects with leprosy had more farmers than the subjects with albinism ( $p < 0.05$ ). Table 1 shows socio-demographic characteristics of the subjects with albinism and subjects with leprosy [20].

**Table 1. Socio-demographic characteristics of the subjects with leprosy and subjects with albinism**

Variables	Subjects with leprosy N (%)	Subjects with albinism N (%)	Statistics
<b>Sex</b>			
Female	43 (43)	63 (63)	$\chi^2=8.03, p=.004, df=1$
Male	57 (57)	37 (37)	
<b>Age</b>			
Mean± SD	43.23±16.9	36.66±16.9	t =3.08, p=0.02,df=6
<b>Marital status</b>			
Married	67 (67)	28 (28)	$\chi^2=35.71, p=0.01, df=1$
Not married	33 (33)	72 (72)	
<b>Educational level</b>			
No formal education	42 (42)	14 (14)	$\chi^2=95.68, p<0.001, df=3$
Formal education	58 (58)	86 (86)	
<b>Employment status</b>			
Not employed	24 (24)	39 (39)	$\chi^2=37.62, p<0.001, df=1$
Employed	76 (76)	61 (61)	
<b>Occupation</b>			
Professionals	11 (11)	57 (57)	p<0.001, df =7.
Clerical/sales workers	23 (23)	32 (32)	
Agricultural workers/craftsmen	60 (60)	6 (6)	
Elementary workers/others	9 (9)	5 (5)	

### 3.2 Quality of Life of Subjects with Leprosy and Subjects with Albinism

Subjects with leprosy had lower QoL scores ( $p < 0.05$ ) than the subjects with albinism in all the 4 domains. Table 2 shows the QoL transformed scores for the subjects with leprosy and those with albinism.

### 3.3 Relationship between Socio-demographic Characteristics and QoL of Subjects with Leprosy or Albinism

The male subjects with leprosy had lower mean QoL scores in all the domains than the male subjects with albinism ( $p=0.02$ ). The female subjects with leprosy had lower mean QoL scores in all the domains than the female subjects with albinism ( $p=0.04$ ). The subjects with leprosy who were not married had lower QoL scores in the social relationship and environment domains ( $t = 2.69, p = 0.01, df = 98$ ). The married subjects with leprosy had lower QoL scores than the married subjects with albinism in the environment domain only ( $t = 2.19, p = 0.04, df = 98$ ). Employed and not employed subjects with leprosy scored lower than employed ( $p = 0.01$ ) and not employed ( $p = 0.03$ ) subjects with albinism in all domains.

Educated and not educated subjects with leprosy scored lower than educated ( $p = 0.02$ ) and not educated ( $p = 0.03$ ) subjects with albinism in all domains. Table 3 shows the relationship between socio-demographic characteristics and QoL of subjects with leprosy or albinism.

## 4. DISCUSSION

The subjects with leprosy had lower quality of life scores than the subjects with albinism in all the four domains. This finding of poor quality of life among subjects with leprosy is similar to the findings by Atsuro et al. [10]. The authors reported that the quality of life of the subjects with leprosy was lower than the control group. Madhavi et al. [21] in India carried out a study aimed at comparing the quality of life of subjects with leprosy with some community members without leprosy. They reported that the quality of life scores of subjects with leprosy was lower than the control. An et al. [22] studied the quality of life of subjects with leprosy in China. They reported that the quality of life of the subjects with leprosy was lower than that of the control. The finding of low quality of life among subjects with leprosy in this study is in keeping with the above studies. The findings may be attributed to the greater physical deformities and psychological morbidity seen in the subjects with

**Table 2. Quality of life transformed scores for subjects with leprosy and subjects with albinism**

Domains	Leprosy (Mean ± SD)	Albinism (Mean ± SD)	t	p	df
Physical	56.00±14.07	70.71±11.93	7.98	<0.001	198
Psychological	53.50±13.45	70.83±14.55	8.75	<0.001	198
Social relationship	55.95±18.19	71.36±18.68	5.91	<0.001	198
Environment	59.17±12.67	75.41±19.32	7.03	<0.001	198
Total	223.57±43.82	287.91±54.03	9.25	<0.001	198

**Table 3. Relationship between socio-demographic characteristics and QoL among the subjects with leprosy and subjects with albinism**

Variables	Physical health	Psychological	Social relationship	Environment
<b>Sex</b>				
<b>Male</b>				
Leprosy n= 57	55.00±13.61	51.56±13.79	55.47±16.22	59.42±10.99
Albino n= 37	71.62±12.35	71.41±14.17	72.54±17.17	77.78±18.32
<b>Female</b>				
Leprosy n= 43	57.33±14.71	56.07±12.69	56.58±20.70	58.84±14.72
Albino n= 63	70.17±11.74	70.49±14.87	70.67±19.61	74.02±18.89
<b>Marital status</b>				
<b>Married</b>				
Leprosy n= 75	50.09±9.43	61.61±7.87	57.41±14.41	52.89±12.73
Albino n= 37	53.24±10.48	61.95±8.23	58.15±13.83	58.75±13.29
<b>Not married</b>				
Leprosy n= 25	54.80±8.20	61.40±12.30	51.60±15.90	51.35±11.17
Albino n= 63	57.01±11.50	63.25±8.73	63.13±16.25	61.74±14.69
<b>Education status</b>				
<b>No formal education</b>				
Leprosy n= 42	53.12±16.24	51.62±14.51	56.10±17.74	56.52±14.33
Albino n= 14	66.71±12.60	67.36±13.29	63.86±22.64	74.24±15.44
<b>Formal education</b>				
Leprosy n= 58	58.09±11.98	54.86±12.57	55.84±18.66	61.09±11.05
Albino n= 86	71.36±11.76	71.40±14.74	72.58±17.81	78.94±19.90

leprosy. It may also be partly attributed to recruitments of the subjects from different settings. The subjects with leprosy were recruited from a Catholic Mission Specialist Hospital in Abakaliki, Ebonyi State. The hospital has 3 major sections- maternity, leprosy and tuberculosis units. Subjects with leprosy were recruited from the leprosy unit of the hospital. The subjects with albinism were recruited from Enugu metropolis in Enugu State. The two locations, though 73 kilometers apart are in south east Nigeria.

In the present study there was more quality of life impairment among subjects with leprosy in all the socio-demographic variables measured compared to the subjects with albinism. One reason may be due to the level of physical deformity associated with leprosy compared to subjects with albinism. Madhavi et al. [21] also reported that the mean quality of life of the male and female subjects with leprosy were lower than the mean quality of life of the male and female controls respectively. This finding corroborates the result by Tsutsumi et al. [20]. The authors reported higher quality of life impairment among

the subjects with leprosy compared with the control. The authors attributed it to the higher psychiatric morbidity associated with leprosy. An et al. [22] reported no association between low quality of life and sex differences or educational level. The variation between this finding and previous findings may be partly due to the different instruments used or the environment from where participants were recruited.

## 5. LIMITATIONS OF THE STUDY

This was a cross sectional study and no cause-effect relationship can be inferred.

## 6. CONCLUSION

The findings in this study indicate lower quality of life scores in all domains in subjects with leprosy compared to the subjects with albinism.

## COMPETING INTERESTS

Authors have declared that no competing interests exist.

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