

# Psychosocial problems in patients with vitiligo in Nigeria

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## Abstract

Vitiligo is a benign idiopathic depigmenting skin disease that can cause profound social embarrassment and psychological turmoil to the affected persons. There is alteration of skin colour and this can be confused with other skin diseases including leprosy, a disease with significant stigmatization even from biblical times. Dermatitis generally because of several myths in the African culture may have a significant impact on a patient's quality of life including the relationship to others, self-image and self-esteem. The extent to which vitiligo affects the emotional and psychological wellbeing of people affected especially in blacks need to be documented and addressed.

Sixty patients with vitiligo in various parts of the body were subjected to an open ended questionnaire to show their perception of the attitude of others to their skin condition and how it affects their relationships with relatives, casual acquaintances and co-workers. Ninety percent of patients were embarrassed about their own lesions. People stared at them, avoided them, made rude remarks, gave derogatory names to their skin conditions and this affected their social interactions and outings. However family and sexual relationships were well preserved.

The support of family members and attending physician can help affected people cope with vitiligo. Cosmetic cover will reduce the embarrassment of the patient. Some of the patients may need counselling and psychiatric consults. Health education on skin diseases to the general public will be useful in alleviating the stigmatization associated with skin diseases.

**Key Words:** Vitiligo, Psychosocial, Stigma

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## Introduction

Skin colouration is part of body image. Smooth homogenous skin colour is seen as part of beauty. Depigmenting dermatosis of which vitiligo is one draws unusual attention to the patient especially when in visible areas of the body. Vitiligo is an idiopathic disorder of pigmentation resulting from destruction of melanocytes and therefore reduction in their number (melanocytopenic disorder)

and not primarily the result of a reduction of melanin synthesis. The skin texture is otherwise normal. The bewildered person already psychologically disturbed by his/her skin changes finds himself/herself an object of unnecessary public focus because of this aberration. The loss of skin pigment therefore poses a severe cosmetic and social problem to the affected.

Biblical time leprosy was associated with isolation of the victim with a terrible social stigmatization because of loss in skin colour [1]. Vitiligo has been confused with leprosy among the inexperienced public [1]. In the treatment of vitiligo, repigmentation is difficult to achieve and in most cases not complete. The health personnel need to be able to identify and allay the fears of patients with vitiligo to improve psychosocial wellbeing of the affected. The stigmatization associated with depigmenting dermatosis need to be documented and addressed. The objective of this study is to identify and highlight the psychosocial problems associated with vitiligo, a depigmenting dermatosis in a black population in Western Nigeria.

## Methodology

The research design was a hospital based non randomised selection study of affected patients presenting in the Dermatology clinic of a tertiary teaching hospital in Western Nigeria over a period of two years. This hospital serves as a referral center. The criteria for diagnosis of vitiligo were clinical based on the following guidelines:

- Acquired idiopathic loss of pigmentation that may be round, oval, irregularly shaped or dermatomal.
- Borders of lesions must be well defined
- There is no alteration of skin texture
- There is no sensory loss and no nerve thickening
- There could be hair involvement and follicular repigmentation
- There could be appearance of lesions along lines of trauma (Koebners phenomenon).

Questionnaires were designed to collect information from each person in the study population and it was in three sections. The first section documented the demographic data of the affected person and whether their vitiligo was in exposed area or not. The second part gave options for the likely causes of vitiligo. Responders were allowed to choose from nine options which included "I don't know". The third part of the questionnaire was a set of direct questions on the attitudes of people around them to their skin problem requiring the responder to tick YES or NO. Each responder was then counselled about the possible causes of vitiligo documented in literature and that the condition is non contagious. It was also stated that the real cause of vitiligo was yet to be known. Assurance was given to the patient that he/she cannot infect someone else. They were also counselled about possibility of cosmetic cover especially for exposed areas to reduce the attention generated by the change in skin colour while receiving definitive therapy.

Sixty patients were recruited into the study but the response to the questionnaire could not be adequately elicited in the two patients below 10 years of age. Responses in 58 affected persons were collated. These questionnaires were pretested. Descriptive statistics was used to analyze the results.

## Results

The number of people presenting with vitiligo during the period of 2 years at this clinic was sixty, with male: female ratio of approximately 2:1. The age range was between 18 months to 70 years of age. The peak age of presentation was between 20-29 years of age [See Table 1]. Eighty seven percent had lesions at visible sites and lesions appeared more extensive in males. Thirty



Figure1: Vitiligo on the upper limb and trunk



Figure 2: Vitiligo on the face

five percent of the affected people had localised lesions while 65% had lesions at more than one site. The localised lesions were focal and segmental types while the generalised were acrofacial, vulgaris and universal.

The occupation and the social status of the people affected varied widely. They included farmers, housewives, students, bricklayers, clerical officers and medical personnel. Responses to the questionnaire were documented. [See Table 2, 3, 4]. Relationships were well preserved in the 37 married people with vitiligo. The vitiligo did not affect their sexual relationships and there was no increase in the number of quarrels, disagreements and separation among couples. There was no significant difference in the psychosocial problems associated by gender. However, relationships with fellow-workers and casual acquaintance were significantly negatively affected.

Social outings were reduced in 41% of affected people. Ninety percent of the people were embarrassed by their own lesions. Derogatory names by which they were called included "leopard skin", "boy with the white nose", "multicoloured", "Rainbow".

People refused sitting next to them, avoided shaking hands and eating around them. Cosmetic cover-up was used especially by females affected. These included gentian violet, lipsticks, brown powder, charcoal and black eyebrow pencils. No patient had intent to commit suicide.

**Table 1: General Group Characteristics**

Age group (years)	Female		Male		Total (N=60)		
	n	%	N	%	n	%	
0 - 9	1	1.65	1	1.65	2	3.3	
10 - 19	2	3.3	8	13.3	10	16.7	
20 - 29	9	15.0	12	20	21	35	
30 - 39	7	11.7	5	8.35	12	20	
40 - 49	2	3.3	6	10	8	13.3	
50 - 59	1	1.65	3	5	4	6.7	
60 - 69	-	-	2	3.3	2	3.3	
70+	-	-	1	1.65	1	1.7	
Marital Status	Married	14	23.3	23	38.3	37	62
	Single	8	13.3	15	25	23	38

**Table 2: Presumed Causes Of Vitiligo**

Causes of Vitiligo	Number of responders	% of responders
Infection	15	26
Leprosy	0	0
Curse	5	8.6
Post-traumatic	5	8.6
Hereditary	10	17.3
Nutritional deficiency	3	5
HIV/AIDS	0	0
Albinism	0	0
I don't know	20	34.5
TOTAL	58	100%

**Table 3: social problems associated with Vitiligo by sex**

Social problems	Female (n=21)		Male (n=37)		Total (N=58)	
	N	%	n	%	n	%
Severed sexual relationships	Nil	0	Nil	0	Nil	0
Severed marital relationships	Nil	0	Nil	0	Nil	0
Unstable Family relationships	Nil	0	Nil	0	Nil	0
Suicidal tendencies	Nil	0	Nil	0	Nil	0
Relationship at work	7	33.3	15	40.5	22	38
Relationships with casual acquaintance	5	23.8	9	24.3	16	27.6

Nil=zero

**Table 4: Psychological Problems Associated With Vitiligo By Sex.**

Psychological problems	Female (n=21)		Male (n=37)		Total (N=58)	
	n	%	n	%	n	%
Staring	18	85	27	73	45	77
Stigmatization	10	47	12	32	22	38
Derogatory remarks	5	23	5	13	10	17

## Discussion

The skin is easily visible to the outside world and therefore is a zone privileged for interactions between the individual and the society. Therefore perception of deviation from normal appearance of the skin may generate a negative response from onlookers. Qualitative and quantitative studies have shown that cutaneous diseases can have significant effects on psychologic wellbeing and social functioning [2,3]. Negative responses are bound to have an adverse effect on the social and psychological wellbeing of sufferers. Zghal *et al* using a group of 60 patients with vitiligo, psoriasis and onychomycosis found that the chronic dermatosis altered the quality of life of the patients especially when located in visible areas especially the face [4]. In this current series eighty seven percent had lesions at visible sites.

The peak age of the persons with vitiligo in this series was 20-39 years of age, keeping with earlier studies documenting that vitiligo was more common below the age of 40 years. Soyinka in his study in 1975 also in Western Nigeria found that his patients with vitiligo presented between the ages of 25-35 years of age [5]. In another series 70% of the study population was below 30 years of age [6]. Vitiligo therefore presents in the productive years when negative psychosocial impact will have vast effect on the economic output of the individual. There was no statistically significant difference between the ages of presentation of males and females ( $p = 0.476$ ). Levais however noted earlier presentations in females [7].

There were various patient responses to presumed causes of vitiligo. A number of 34.5% of the responders said they had no idea of what causes the condition. Surprisingly none of the patients thought that it was caused by Leprosy, a disease that could easily has been confused with vitiligo. In India vitiligo is described as "white leprosy" (Shweta Kusham or Dhval Khushta) thus confusing it with Leprosy [1]. Twenty six percent of responders think that vitiligo was caused by an infection of some sort, while 17.3% thinks it is inherited. Although an involvement of genetic factors is assumed, vitiligo is not simply an inherited disorder. There is a familial aggregation of vitiligo and this is statistically significant at the 5% level [8]. In some cases polygenic nature

of the disease is assumed and there is a controversial discussion about the hereditary nature of vitiligo till now. The disease does not appear to be inherited in a simple dominant or recessive fashion but rather associated with genetic loci on different chromosomes [8]. Soyinka in Ife, Nigeria was able to identify one occurrence of vitiligo in a set of monozygotic twins with a history of 5 years separating the onset of vitiligo between the first twin and his brother [5]. Lerner noted that some of his patients actually attributed their vitiligo to injury and 38% of his 200 patients had family history of vitiligo [9].

The patients in this series enjoyed support from their spouses and family members. In a study by Judith Porter *et al*, people with vitiligo received negative response from their friends and families [10]. The effect of race on reaction to impaired appearance was explored in a sample of 158 patients with vitiligo [11]. Psychological coping resources and variables related to negative labelling of the stigma are associated with variation in degree of disturbance. Self-esteem and perceived stigmatization are associated significantly with degree of disturbance among both Blacks and Whites. Gender, age, and visibility of the condition are not related to difference in degree of disturbance within either race, although there is some evidence that they may have an indirect relationship to degree of disturbance. Family support systems are well established in African culture even in the presence of disease and this is evidenced in the response observed in family members of our clients. Relationships were well preserved in the 37 married people with vitiligo. The vitiligo did not affect their sexual relationships and there was no increase in the number of quarrels, disagreements and separation among couples. There was no significant difference in the psychosocial problems associated by gender. In Porter *et al* series, the majority of patients who reported a negative impact on sexual relationships attributed the problems to their embarrassment [12]. Those who were particularly affected were those with low self-esteem, men, those to whom appearance is important, and single persons. In India, vitiligo is known as white leprosy and is associated with loss of marital prospects and suicidal tendencies [8]. Under the Hindu culture of arranged marriages, it is almost impossible for a young girl with extensive vitiligo to be given out in marriage [8].

Relationships with fellow-workers and casual acquaintance were significantly negatively affected. The traders among them noticed a gradual decline in customer patronage and one person needed a medical report to his employers to confirm that he was not suffering from leprosy. There was no case of job termination. In the United States, studies have shown that it affected the professional life of sufferers [13].

Many persons with vitiligo show indications of significant distress that are related to specific types of social encounters and emotional disturbance. Analysis of the qualitative data indicated that vitiligo affects lives in a variety of ways consistent with perceived stigma and that some categories of response such as avoidance of activities and negative reactions by others were associated with higher General Health Questionnaire scores [14]. People stared unduly long at people with vitiligo and made rude remarks at them. This is similar to the results of the study done by Judith Porter *et al* in 1987. Fifty seven percent of her patients complained that people unduly stared at them, 20% had been victim of rude remarks and 8% encountered job discrimination as a result of their disease [10]. Barbee and Sumner as far back as 1951 found that their patients with vitiligo had inferiority complex, resentment, shame and seclusion [15]. This could be exaggerate their perception of negative responses from people.

Dermatologists are likely to be confronted with skin conditions which present with a wide range of psychiatric issues and problems one of which is vitiligo. Documenting the psychosocial impact is important for total management of the people affected. The chronic dermatosis including vitiligo definitely alters the quality of life of patients [4].

Vitiligo is said to be associated with high psychiatric morbidity creating a need to develop cross-

cultural database on psychosocial aspects and psychiatric morbidity associated with it [16]. The use of decorative cosmetics in disfiguring skin diseases is an effective, well tolerated measure increasing the patients' quality of life [4, 6]. Decorative cosmetics can complement the treatment of disfiguring skin diseases like vitiligo. The coping strategies employed by patients in the current series included use of cosmetics, covering clothing for areas affected and avoiding social functions. Cosmetics used included brown powders, lipsticks, eyebrow pencils, charcoal and gentian violet.

There are many other treatment options that can be offered to patients with vitiligo. Nonsurgical repigmentation therapies are the first-line active treatment and includes the use of topical or oral psoralen with ultraviolet A light (PUVA) and use of corticosteroids. Corticosteroids can be applied topically, orally or intralesionally. Oral and topical Khellin plus UV-A, UV-B narrowband and broadband can also be used [17, 18]. In vitiligo cases that are resistant to conventional medical therapy, various modalities of surgical management include camouflage tattooing, melanocyte transplant, excision and melanocyte culture [19].

### Conclusion

Vitiligo is a progressive disfiguring condition involving a loss of skin pigmentation and no rapid effective treatment or cure exists. Although vitiligo's medical effects have been studied extensively, little attention has been paid to its psychological impact or to the effects of psychological state on the illness itself. The society is ill informed about the aetiopathogenesis and the plight of vitiligo sufferers. Many persons with vitiligo show indications of significant distress that are related to specific types of social encounters and emotional disturbance.

### Recommendations

Support of family members and attending physician is indispensable in the management of vitiligo. The sharing of experiences with co sufferers in an organized forum to lessen the burden of stigmatization is recommended. Vitiligo friendly groups and forums can be set up at referral dermatology centres. Cosmetic cover up can be encouraged and improved upon. Further work on acceptable, available, affordable cosmetic alternatives free of allergic reactions should be undertaken. Psychiatric assessment and services should be made available. Counselling sessions is essential and psychotherapist should participate in the management of the psychosocial problems of these persons. Further work for more effective therapeutic modalities is advocated. Local herbal preparations and alternative therapy need to be looked into.

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