

# **QUALITY OF LIFE AMONG VITILIGO PATIENTS ATTENDING DERMATOLOGY OUT-PATIENT CLINICS IN JOHANNESBURG**

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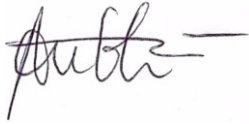


A research report submitted to the Faculty of Health Sciences, University of the  
Witwatersrand, Johannesburg, in partial fulfillment of the requirements for the degree  
of  
Master of Medicine in the discipline of Dermatology

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## **DECLARATION**

I, Elisah Agaba declare that this research report is my own work. It is being submitted for the degree of Master of Medicine in the branch of Dermatology in the University of the Witwatersrand, Johannesburg. It has not been submitted before for any degree or examination at this or any other University.

A handwritten signature in dark ink, appearing to read 'Elisah Agaba', with a horizontal line extending to the right.

**Elisah Agaba**

14<sup>th</sup> day of June 2017

In loving memory of my mother

Elisabeth Mukakibibi

1934- 2010

## **ABSTRACT**

**Introduction:** Vitiligo is a skin pigmentation disorder and has an estimated global prevalence of around one to two percent. Vitiligo can significantly affect patients' Quality of life (QoL). It is cosmetically and psychologically devastating, and can affect anyone irrespective of race, skin type or ethnicity. There is a paucity of research evaluating the QoL amongst vitiligo patients in Africa and Sub-Saharan Africa in particular. The objectives of this study were to demonstrate how vitiligo has altered the QoL of vitiligo patients treated at the skin outpatients' clinics in Johannesburg, South Africa.

**Methods:** Our research was a prospective cross-sectional study of all individuals who were diagnosed with vitiligo at the three dermatology outpatients' clinics in three academic public hospitals, and the phototherapy daycare centre in Johannesburg. All patients fulfilling the inclusion criteria were requested to take part in the study. Data was obtained from enrolled individuals using a data collection sheet and the Dermatology Life Quality index questionnaire. This information was analysed using statistical software (STATA version 12).

**Results:** A total of ninety-five (n=95) respondents were included as per inclusion criteria in our study. Our cohort comprised of sixty-two females (n=62, 65.26%), thirty-three males (n=33, 34.74%). DLQI scores were in the ranges of 0 to 28 and the mean was  $10.06 \pm 6.52$ , which indicates a moderate Quality of life (QoL) impairment in our cohort.

**Conclusion:** Our study has shown that vitiligo moderately affects the QOL life of adult South African vitiligo patients. Therefore, treatment measures should be directed towards medical and psychological aspects of our patients for better treatment outcomes and improved QoL. This would be an argument for establishment of psychodermatology clinics at our referral hospitals.

## **ACKNOWLEDGEMENTS**

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## **NOMENCLATURE**

CEO: Chief Executive Officer

CMJAH: Charlotte Maxeke Johannesburg Academic Hospital

CHBAH: Chris Hani Baragwanath Academic Hospital

HJH: Helen Joseph Hospital

DLQI: Dermatology Life Quality Index

MS: Microsoft

QoL: Quality of Life

SD: Standard deviation

UK: United Kingdom

VitiQoL: vitiligo-specific Quality of life instrument

VSSA: Vitiligo Society of South Africa

## **PREFACE**

Vitiligo was ranked the fourteenth most common Dermatological condition in 2003 in a study conducted in the five public academic hospitals in Johannesburg. (1) Various studies have shown that several skin diseases, along with vitiligo, affect the QoL of patients. (2-10) To our knowledge, no other study has been done in South Africa to evaluate the QoL of individuals with vitiligo. Our research is a prospective cross-sectional study to assess the QoL of all patients meeting the inclusion criteria seen from October 2012 to January 2013 at three dermatology outpatient clinics in three respective academic public hospitals in Johannesburg. Patients attending the phototherapy daycare centre at CMJAH for phototherapy treatment of vitiligo were also requested to be included among our respondents.

## **CHAPTER 1**

### **1.0 INTRODUCTION**

Vitiligo is a pigmentation disease with a global prevalence estimated to be around 1–2 percent. (11) It presents with well-demarcated areas of pigment loss, usually symmetrical, due to loss of pigment cells. Melanocytes that normally produce skin pigment called melanin, which characterise skin colour, are lost from the affected skin. The mechanism(s) that cause their loss are not known to date. Vitiligo may appear at any time from very young age to senescence. (12) It may be localised, generalised and universal (loss of skin colour covering almost or the whole body surface). A completely amelanotic macule (or patch), surrounded by apparently normal skin is the type of vitiligo seen most frequently. It commonly appears uniformly milk or chalk-white. (11, 12) Its natural course is unpredictable, and there is currently no known definite universal cure. (13)

#### **Epidemiology of Vitiligo**

Approximately 50 million people worldwide are affected by vitiligo. Globally, epidemiological studies have been done regarding vitiligo but there is limited epidemiological data in Africa and much so in South Africa in particular. The number of vitiligo patients in the UK is greater than half a million individuals. (14). In 2005, vitiligo was diagnosed in 25 (3.4%) of patients at a University Teaching Hospital in Nigeria. (15) The hospital-visiting rate prevalence of vitiligo in Korea during a three-year duration was 0.12% to 0.13%. (16) Vitiligo meanwhile contributed 18.9% of the etiologies of acquired hypochromic patches in Bamako, Mali. (17) Vitiligo is common in South Africa, and was

ranked by Hartshorne as the fourteenth most common dermatological disease in a study conducted in the five public academic hospitals in Johannesburg in 2003. (1)

### **Causes and association with other diseases**

The causes of vitiligo are multifactorial including genetic and nongenetic factors. Twin and family studies have indicated the importance of genetic factors in the development of vitiligo. In these studies, a number of genes have been found to be vitiligo susceptible and most of them are also associated with other autoimmune diseases. Vitiligo can appear with or as a manifestation of several medical conditions. These diseases including Hashimoto thyroiditis, Graves' disease, alopecia areata, myasthenia gravis, psoriasis, systemic lupus erythematosus, Sjogren's syndrome, atopic dermatitis and *Helicobacter pylori* (HP) infection were found to be associated with vitiligo. (16, 18-21)

### **Clinical Presentation**

Vitiligo presents with well-demarcated areas of pigment loss, usually symmetric. These vitiligo macules and patches are surrounded by normal skin and have discrete margins. The shape can vary from round, oval, irregular or linear. These lesions enlarge outwards over time as the disease progresses. This enlargement may be very slow almost to static or rapid depending on an individual. It is not known why this process is quick in some individuals and very slow in others. The course of the disease is unpredictable and vary between individual patients. Vitiligo lesions are less apparent in lightly pigmented individuals in contrast to darkly pigmented people where they are more visible. This is because of the contrast between vitiligo lesions and the surrounding normal dark skin. Vitiligo is usually asymptomatic but pruritus is sometimes reported by some patients. Various classification systems for vitiligo have been suggested, leading to confusing terminology but generally it is classified as

localized, generalized and universal. Its localized when one area of the body or a unilateral segment is involved and is generalized when several parts of the body are affected. Universal vitiligo is where almost or the whole body is depigmented.

## **Treatment**

Although there is no known definitive universal cure, available treatment options lead to satisfactory results in a good number of patients. Several treatment options are available and some are associated with side effects during their long-term use. Unfortunately, those with less or no side effects are limited or even not available at all in most health facilities. Some of the common treatment options are briefly discussed here. Corticosteroids can be used topically, intralesional or systemic but these are associated with side effects like skin atrophy. Topical calcineurin inhibitors including tacrolimus and pimecrolimus in form of ointment or cream can be used alone or in combination with topical steroids or phototherapy. These help to minimise the side effects of topical steroids. Unfortunately, topical calcineurin inhibitors are not available in resource limited hospital settings. Photo(chemo)therapy is also used; narrowband UVB has shown to be more effective than broadband UVB in the treatment of vitiligo. Short-term side effects include pruritus and xerosis. Surgical therapies are indicated for those patients who do not respond to medical treatment and are limited in most centres. Surgical options include minigrafting, grafting of cultured autologous melanocytes and others. Complete depigmentation is also a treatment option for those patients with widespread vitiligo who have only a few areas of normally pigmented skin in exposed parts of the body. Various therapeutic options can be combined to produce higher rates of success compared to monotherapy. Psychological support is of great importance in these patients.(11) Use of support groups and psychological counselling depending on the patient states is also helpful.

## **Psychosocial burden of vitiligo**

It is well known that vitiligo adversely affects the psychosocial aspects of vitiligo sufferers. It was reported in a study done at Khartoum Dermatologic Hospital in Sudan that suffering from vitiligo is responsible for psychological problems in a large number of vitiligo patients. (22) Vitiligo is cosmetically and psychologically devastating, and affects people of all races, skin types and various ethnic groups. (23) Due to the contrast between diseased and normal skin, patients with skin of colour are greatly affected both psychologically and socially. Therefore, the QoL may vary in different racial groups. (24) Vitiligo can significantly affect patients' QoL, especially when it is on the exposed body parts or the genital area. (25) The QoL is altered in a significant number of individuals, despite the body surface area involved (generalised/localised vitiligo). Therefore, patients presenting with localised vitiligo may also have remarkable effects on QoL. (2) It was shown that the burden on QoL increases proportionally with extent of the disease, and may also involve sexual dysfunction and itching. Furthermore, various distributions of the disease match various forms of QoL impairments. (26) The Vitiligo Society of South Africa (VSSA) was established in May 2008 due to the burden of vitiligo in South Africa. (27)

## **The concept of quality of life in general and its assessment in Vitiligo**

'Quality of life' is a concept that was formulated from an arrangement of information about physical, social and psychological wellbeing of a person. This was promoted by the World Health Organisation as not only the absence of disease or infirmity, but as the ability of a person to be able to live a productive and enjoyable life. (28) QoL evaluation collects information from the patient about how he/she feels the effect of the diseases on his/her everyday life. This will be used to assess the benefits of treatment/management systematically and scientifically, as this is based on what is important to the patient. (29)

Various QoL assessment tools can be used to demonstrate the details of the burden caused by vitiligo, and some of these questionnaires are the Dermatology Life Quality Index (DLQI), the Dermatology-specific quality of life, the Skin Index, and the vitiligo-specific Quality of Life Instrument. (23, 29-31)

Studies evaluating the QoL amongst vitiligo patients have been published, however, the majority of these studies are from Europe. (3-5) Other studies on vitiligo and QoL were conducted amongst an Asian population. Su-ming Wong et al. in Malaysia, in their study, evaluated the QoL among Malaysian patients with vitiligo and found a moderate limitation on the QoL of their respondents. (6) Parsad et al. in India evaluated the DLQI score in their patients, and then how it affects the outcome of treatment. In this study, a mean DLQI score of 10.67 was reported, which is higher than that obtained in Malaysia of 6.40. This shows how vitiligo can affect patients differently in terms of their QoL, in different populations. It has been shown that vitiligo affects the quality of life of individuals from the same family, including those without disease, and sometimes may greatly affect considerable number of aspects of their daily living. (7, 32)

In Africa, few studies on QoL and skin diseases in general and on vitiligo in particular have been undertaken. (9, 10, 33-35) Osman et al. in Sudan studied the psychological disturbances due to vitiligo in adult Sudanese vitiligo patients. Vitiligo was found to cause many more psychiatric disturbances than albinism in Nigeria among African adult subjects in a study done at a tertiary hospital. (22, 36)

There are few studies evaluating the QoL among patients with vitiligo in Africa; Samson Kiprono et al. studied the QoL of vitiligo patients in Tanzania at the Regional Dermatology Training Center. (8) In South Africa, studies to evaluate the QoL of South Africans with other chronic skin diseases that affect their QoL have been carried out. (9, 10) Using PubMed

and Google scholar literature search, it would appear that no study on QoL and vitiligo has been conducted in South Africa.

Therefore, our aim was to demonstrate how vitiligo has altered the QoL of our patients in South Africa. It was a valuable opportunity to evaluate the influence of skin color on QoL impairment, since patients with different skin photo types were enrolled.

### **1.1 STUDY OBJECTIVES**

- 1) To evaluate the quality of life of vitiligo patients.
- 2) To describe the demographic characteristics of vitiligo patients attending dermatology outpatient clinics.
- 3) To test for associations between demographic characteristics and QoL.
- 4) To determine treatment modalities (phototherapy, topical steroids and others).

## **CHAPTER 2**

### **2.0 MATERIALS AND METHODS**

Our study was a prospective cross-sectional study. We involved all patients meeting the inclusion criteria seen from October 2012 to January 2013 at CMJAH, CHBAH and HJH in Johannesburg. Patients attending the phototherapy daycare centre at CMJAH for phototherapy treatment of vitiligo and were meeting the criteria to be in the study were requested to be interviewed about their condition, and were added into our cohort. All patients who were meeting the inclusion criteria accepted the request to participate in the study.

After obtaining ethics approval from the University of the Witwatersrand's Ethics Committee on Human Research, and gaining permission from the CEOs of various health facilities, data was obtained from participants using the data collection sheet and DLQI questionnaire. This data was cross-checked and coded for subsequent statistical analysis.

#### **2.1 STUDY DESIGN**

This is a prospective cross-sectional study assessing the QoL among all patients with vitiligo who consented to participate in this research. These patients were seen at the dermatology outpatients' clinics at CMJAH, CHBAH and HJH as well as patients attending the phototherapy daycare centre at CMJAH.

##### **2.1.1 Study population**

The academic division of dermatology of The University of the Witwatersrand provides dermatological care to patients in the three public hospitals: CMJAH, CHBAH and HJH.

Patients with different skin phototypes attend these clinics. All patients aged 18 years and above who were diagnosed with vitiligo by a skin specialist, and were attending the dermatology outpatients' clinics at CMJAH, CHBAH and HJH; as well as patients attending the phototherapy daycare centre at CMJAH, either as a new patient or as a follow-up case from October 2012 to January 2013, were recruited to participate in the study.

### **2.1.2 Sampling**

Convenience sampling was employed. A total of 95 (ninety-five) patients that satisfied the criteria below to be included were asked to take part in our study. None of our patients objected the request

Inclusion criteria:

1. Outpatient diagnosed with vitiligo by a dermatologist clinically.
2. Adult patient (Age $\geq$ 18 years).
3. Acceptance to take part in the study.

Exclusion criteria:

1. Inpatient.
2. Less than 18 years of age.
3. Patient who didn't accept to take part in the study.

## **2.2 MEASUREMENTS**

The aim and nature of the study was explained by the investigator to all patients meeting the above inclusion criteria, and these patients were requested to take part in our study. Those who volunteered to participate were asked to sign a consent form. Information regarding demographic characteristics of the patient (example gender, age, and marital status etc.), clinical data on the localisation and the area of coverage of disease, treatment modality and the type of vitiligo after a clinical evaluation by a dermatologist was collected on a data collection sheet. The so-called ‘rule of 9s’ was used to measure the extent of the affected body surface.

The English version of a widely validated questionnaire commonly used in quality of life studies, the Dermatology Life Quality Index, was administered. To overcome literacy and language differences; one of the nursing staff was asked to help with interpretation and translation to the respondents who were not fluent in English for both questionnaire and consent form. All recommendations for its clinical use were followed as outlined by the authors. This questionnaire is user-friendly, and has been used in several other studies assessing QoL in other chronic skin diseases. (9,10) DLQI questionnaire is made up of ten questions with a maximum of four points each, the answers of each question range from ‘not at all’ to ‘very much’, which are scored from zero to three. If the patient answers ‘not relevant’, a score of zero is given. The total score is obtained by adding up the values of each question, which gives a total of 0 to 30, therefore 0 is the possible minimum total score, and 30 is the possible maximum total score. The patient’s QoL is more greatly affected as the total score increases. Scores have the following meanings according to authors: zero to one stands for no effect of the skin condition on the QoL of the patient, two to five are interpreted

as a small effect of the skin disorder on patient's life, six to ten means that patient's life is affected moderately by the skin disorder. Also, scores from eleven to twelve stands for a very large effect on the patient's QoL by the skin condition; if the skin condition has extremely affected the life of a patient, then scores of twenty-one to thirty are given when evaluating the effect of a skin disease on the QoL of patients. An alternative way to express the DLQI is as a percentage of the added scores to thirty. We did not use the VitiQoL, because this instrument was developed recently, and is still in preliminary validation process. (30)

## **2.3 DATA PROCESSING AND ANALYSIS**

### **2.3.1 Data entry**

Information from the questionnaire and the data collection sheets were captured into a Microsoft Excel spreadsheet for the reasons of cleaning and coding of the data. Cleaning was done by rechecking the data for possible missing values, extreme values, as well as verifying for internal consistency. For the purpose of data analysis, data coding was done, for example, the QoL scores of patients with vitiligo were summed up and categorised into their respective groups.

### **2.3.2 Data analysis**

The cleaned and coded data in MS-Excel spreadsheet was transferred to statistical software (STATA version 12) for analysis. To assess patients' demographic characteristics, we carried out descriptive analysis. Categorical variables such as race, gender and treatment modalities, frequencies and percentages were computed, whereas means and standard deviations were computed for numerical variables. To calculate the DLQI, we added up the score of each question, as well as the scores of all patients. The possible sum of the score ranges from a minimum of 0 to a maximum of 30. This information was presented in frequency tables and

bar graphs. For abnormally distributed data, medians and inter-quartile ranges were employed. Various statistical tests (Chi-square, ANOVA test) were used to test for associations between demographic characteristics (race and gender) and QoL. The significant test is set at  $p < 0.05$ .

## **2.4 LIMITATIONS**

Patients were enrolled from tertiary health facilities, and therefore are mainly referred patients. These may be either those who didn't respond to treatment at a lower level, or those who were greatly concerned about their skin condition, with a high total score not reflecting the true image of the effect of the disease on the QoL of patients in South Africa. Our study involved a limited sample, because these patients are referred to tertiary health facilities. There may therefore be a bias present.

A majority of patients attending these public academic hospitals are black, due to their relative socio-economic status compared to that of other races. Due to higher colour contrast between normal and diseased skin in patients with skin of colour, and their large number compared to other races, there may be a bias when comparing the quality of life in this cohort.

## **2.5 ETHICS**

The research proposal was submitted to the University of the Witwatersrand's Ethics Committee on Human Research for assessment and approval before starting of this research. The clearance certificate number M121031 was obtained. Patient information was only used for this research, and details were kept confidential. In order to keep confidentiality of the respondent, coded names were used at every step for the entire study. The consent was obtained from CEOs of various health facilities, as well as from individual participants, before the start of data collection. One of the nursing staff was asked to help with

interpretation and translation of the content of the consent form and everything about the study for those patients who were not fluent in English.

## **CHAPTER 3**

### **3.0 RESULTS**

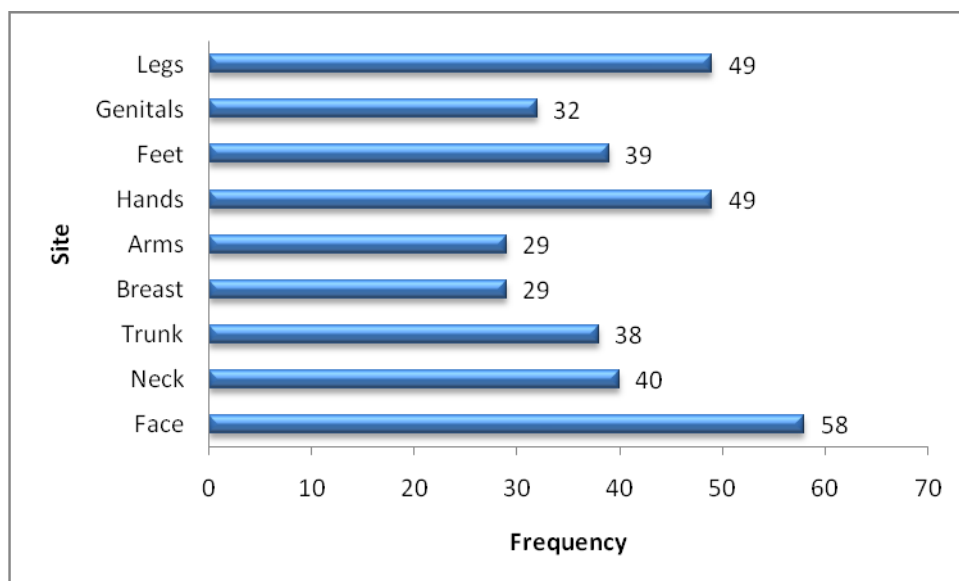
#### **3.1 DEMOGRAPHICS AND CLINICAL CHARACTERISTICS**

A total of ninety-five (n=95) patients took part in our study. Our cohort comprised sixty-two females (n=62, 65.26%), and thirty-three males (n=33, 34.74%). A large number of our patients were between thirty-five and sixty years of age (n=52, 54.7%), followed by those who were above sixty years of age (n=24, 25.2%), and a small number less than thirty-five years of age (n=19, 20%). A majority of our patients identified as black (n=79, 83.16%), followed by those identified as coloured (n=12, 12.63%), where those identified as Indian and white (n=2, 2.11% each) were equal in number. Our patient's age ranged between 18 to 79 years, and the mean was 48.8 (SD=15.7) years. Ninety-four (n=94) of our patients were South Africans, and only one (n=1) patient was a Ugandan. A majority (n=43, 45.26%) of our patients were married, and only five (5.26%) were widowers. Thirty-seven patients were single (n=37, 38.95%). Ten (n=10, 10.53%) patients were divorced. The age at onset of the disease ranged from one year to seventy-seven years, with the mean age at onset of 39±17.9 years. Table 1 below shows detailed characteristics of our patients.

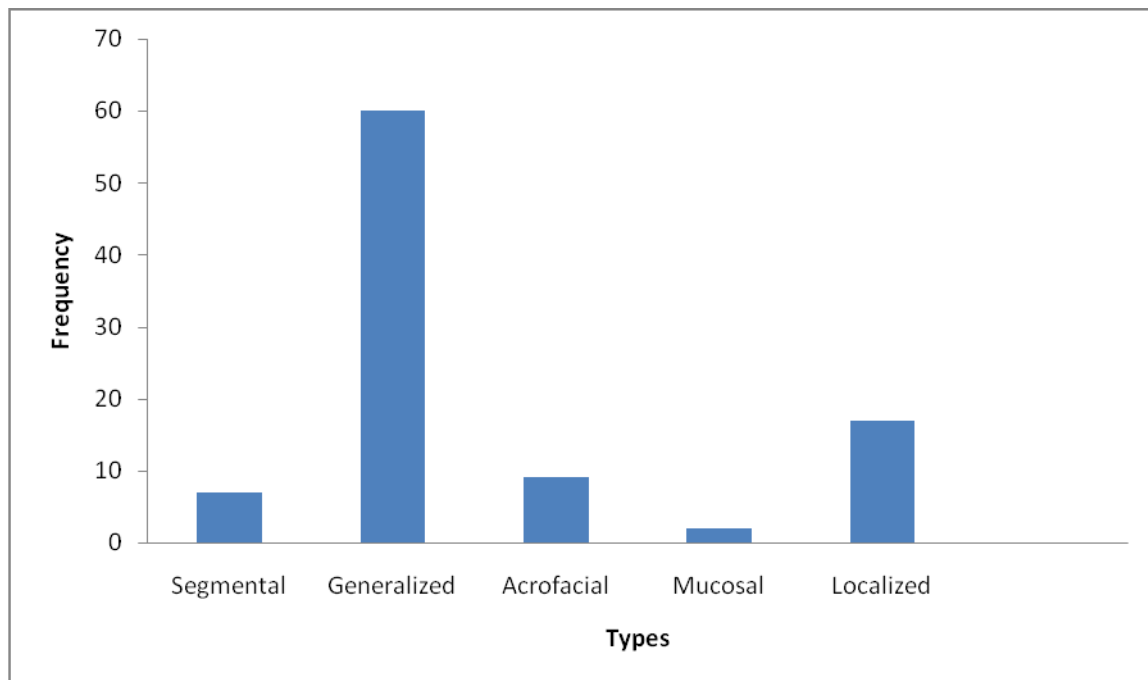
**Table 1 Details of characteristics of all patients enrolled in the study**

| <b>Patients' characteristics</b>                    |                         | <b>Total number of patients (n=95)</b> |
|-----------------------------------------------------|-------------------------|----------------------------------------|
| <b>Age (years), mean(range)</b>                     |                         | 48.8(18-79)                            |
| <b>Gender, n (%)</b>                                | Male                    | 33(34.7)                               |
|                                                     | Female                  | 62(65.3)                               |
| <b>'Race', n (%)</b>                                | Black                   | 79(83.2)                               |
|                                                     | White                   | 2(2.1)                                 |
|                                                     | Indian                  | 2(2.1)                                 |
|                                                     | Coloured                | 12(12.6)                               |
| <b>Nationality (%)</b>                              | South African           | 94(98.95)                              |
|                                                     | Foreigner               | 1(1.05)                                |
| <b>Marital status n (%)</b>                         | Single                  | 37(38.95)                              |
|                                                     | Married                 | 43(45.3)                               |
|                                                     | Divorced                | 10(10.5)                               |
|                                                     | Widower                 | 5(5.3)                                 |
| <b>Occupation n (%)</b>                             | Pensioner               | 19(20)                                 |
|                                                     | Civil Servant           | 19(20)                                 |
|                                                     | Unemployed              | 16(16.8)                               |
|                                                     | Business Person         | 9(9.5)                                 |
|                                                     | Other                   | 32(33.7)                               |
| <b>Family history of Vitiligo, n (%)</b>            | Yes                     | 18(18.95)                              |
|                                                     | No                      | 77(81.1)                               |
| <b>Age of onset (years), mean (range)</b>           |                         | 39.2 (1–77)                            |
| <b>Duration of disease (years), mean (range)</b>    |                         | 9.2 (0.1–46)                           |
| <b>Body surface area involved (%), mean (range)</b> |                         | 19.2(1–95)                             |
| <b>Treatment modality, n (%)</b>                    | Topical corticosteroids | 89(93.7)                               |
|                                                     | Phototherapy            | 8(8.4)                                 |
|                                                     | Other                   | 2(2.1)                                 |
| <b>Dermatology Life Quality Index, mean (range)</b> |                         | 10.06 (0–28)                           |

A family history of vitiligo was found in eighteen (n=18, 18.95%) patients. Generalised vitiligo was the commonest (n=60, 63.16%) type, and mucosal vitiligo was the least (n=2, 2.11%). Exposed areas like the face (n=58, 61.05%), hands (n=49, 51.58%), legs (n=49, 51.58%) and neck (n=40, 42.11%), were frequently affected. Genitals were involved in thirty-two (n=32, 33.68%) patients. Using the rule of nine, the involved body surface area was in the ranges of one (1%) to ninety-five percent (95%). Mean body surface area involved was nineteen (19.2%, SD=24.4) percent. Most (n=89, 93.86%) of our patients were on topical steroids as their treatment modality and only eight (n=8, 8.42%) patients were on phototherapy. Two (n=2, 2.13%) patients were attending a traditional healer.



**Figure 1 Localisation of Vitiligo**



**Figure 2 Types of Vitiligo**

### **3.2 QUALITY OF LIFE (QoL)**

The DLQI scores were ranging from 0 to 28 and the mean score was  $10.06 \pm 6.5$ , which indicates moderate Quality of Life (QoL) impairment in our cohort. Symptoms and feelings of our patients were commonly affected, with twenty-seven patients feeling highly embarrassed of their skin condition ( $n=27$ , 28.42%), where nineteen ( $n=19$ , 20%) had an itchy skin, and or found their skin painful or stinging.

The mean DLQI scores in females was higher than it was in males, but that was not significant difference ( $P$  value=0.6). The mean DLQI scores increased with skin contrast, with those identified as white having the least (8), those identified as black and colored having the highest (10.06 and 10.58, respectively), with 9.5 for those identified as Indians.

The difference was not statistically significant between different DLQI scores of various races, using ANOVA test.

Individuals who were divorced had the highest mean DLQI score (11.2), widowers had the lowest (8), while the mean DLQI scores for unmarried and married individuals were 10.51 and 9.65, respectively. Using the ANOVA test, there was no statistical difference between DLQI scores in different marital status.

The highest mean DLQI score was seen in unemployed individuals (13.4), where those doing business had the lowest (7.5). Pensioners, government employees and those doing other activities like traditional healers had mean DLQI scores in the same range (9.8, 9.7 and 9.3). Individuals aged less than 35 years and those between 35 and 60 years had a mean DLQI scores of 10.8 and 10.2, respectively, while the mean DLQI score of people aged above 60 years was 9.0, so there was a decrease in mean DLQI score as age increases, but this was not statistically significant using ANOVA test (P value =0.67).

Patients who were undergoing phototherapy had a mean DLQI score of 13.8, compared to those who were not undergoing therapy, whose mean DLQI score was 9.7. The mean DLQI scores for patients on topical steroids and other treatment modalities were 10.07 and 8.5, respectively. Only seven (7) patients were on combination therapy, with a mean DLQI score of 15.8.

Patients with generalised vitiligo had the highest mean DLQI score of 10.88, while those with segmental vitiligo had the lowest mean DLQI score of 7.14. Patients with mucosal vitiligo had mean DLQI score of 10, whereas for those with acrofacial and localised vitiligo were

10.22 and 6, respectively. No relationship between body surface area involved and DLQI scores seen ( $P$  value  $> 0.05$ ). DLQI scores did not statistically correlate with the duration of the disease.

Table 2 below shows a comparison of mean DLQI scores and various patient characteristics

**Table 2 Comparison of mean DLQI scores and various patient characteristics**

| Patient variables         |                                      | Mean DLQI | p-value |
|---------------------------|--------------------------------------|-----------|---------|
| <b>Gender</b>             | Male                                 | 9.4       | 0.7     |
|                           | Female                               | 10.4      |         |
| <b>Race</b>               | Black                                | 10.06     | >0.05   |
|                           | White                                | 8         |         |
|                           | Indian                               | 9.5       |         |
|                           | Coloured                             | 10.58     |         |
| <b>Marital status</b>     | Single                               | 10.5      | >0.05   |
|                           | Married                              | 9.6       |         |
|                           | Divorced                             | 11.2      |         |
|                           | Widower                              | 8.0       |         |
| <b>Occupation</b>         | Pensioner                            | 9.88      | >0.05   |
|                           | Civil servant                        | 9.78      |         |
|                           | Unemployed                           | 13.38     |         |
|                           | Business person                      | 7.5       |         |
|                           | Other                                | 9.3       |         |
| <b>Age groups</b>         | Less than 35 years                   | 10.8      | 0.67    |
|                           | 35 years to 60 years                 | 10.2      |         |
|                           | Above 60 years                       | 9.0       |         |
| <b>Treatment modality</b> | Currently on phototherapy            | 13.87     | >0.05   |
|                           | On treatment other than phototherapy | 9.71      |         |
| <b>Type of Vitiligo</b>   | Segmental                            | 7.1       | >0.05   |
|                           | Generalised                          | 10.9      |         |
|                           | Acrofacial                           | 9.2       |         |
|                           | Mucosal                              | 10.0      |         |
|                           | Localised                            | 8.9       |         |

## **CHAPTER 4**

### **4.0 DISCUSSION AND CONCLUSIONS**

#### **4.1 DISCUSSION**

##### **Mean dermatology life quality index score**

To our knowledge, our study is the first of its kind in South Africa looking at the QoL of patients suffering from vitiligo. The DLQI scores of our patients ranged from 0 to 28 and their mean was  $10.06 \pm 6.52$  which indicates moderate Quality of life (QoL) impairment. This is slightly lower than the mean DLQI score  $\pm$ SD of  $10.67 \pm 4.56$  reported by Parsad et al. in India, but much lower than 14.72 found by Al Robae et al. in Saudi Arabia. (7, 37) In our study the mean DLQI score ( $10.06 \pm 6.52$ ) is slightly higher than that found by Belhadjali et al. of  $9.4 \pm 4$  in France; much higher than that found by Wong et al. of 6.40 in Malaysia; by Kiprono et al. of 7.20 in Tanzania; by Dolatshahi et al. of 8.16 in Iran; by Kostopoulou et al. of 7.17 in France; and by Radtke et al. of 7 in Germany. (6, 8, 38-41) It is important to note that except for the results from the Tanzanian study, most of other studies were from mainly lightly skinned patients compared to our patients where the majority were black patients.

##### **Demographic characteristics and quality of life**

In our study, as in previous studies, females constituted the majority of participants ( $n=62$ , 65.26%), almost two times the number of males ( $n=33$ , 34. 74%). It has been reported that women have a greater feeling of embarrassment and are more concerned about the disease, seeking out medical care more often than men. (5, 17, 34) In our study, gender or marital status did not statistically relate to DLQI scores, which was also demonstrated in the studies done in Malaysia and France. In contrast, in one study done in Belgium, sex was significantly

associated with the DLQI Score, and in general, women had higher scores and a mean of 6.45, whereas men had a mean of 3.13. (5, 6, 40) Significant variation of DLQI scores between males and females was also reported in Iran, France and Germany, in contrast to studies done by Kent et al. and Parsad et al. (7, 38, 41-43)

A decrease in a mean DLQI score, with an increasing age, was observed, though this was not statistically significant. (P-value=0.67) Individuals aged less than 35 years and those between the age of 35 and 60 years had mean DLQI scores of 10.8 and 10.2, respectively, while it was 9.0 for patients aged above 60 years. Young people are more likely to be concerned about the appearance of their skin. The same findings were reported by Radtke and his colleagues (41)

### **Quality of life and disease characteristics**

The symptoms and feelings of our patients were commonly affected, with twenty-seven (n=27, 28.42%) patients feeling great embarrassment or concern about the appearance of their skin, where nineteen (n=19, 20%) had an itchy and/or painful or stinging skin. This is the same as findings by Wong and Bab, where several of their patients were embarrassed because of their skin disease, and others had itchy skin at vitiliginous areas. (6) In this study, 62.5% of patients with itchy skin were on phototherapy treatment during the time when the study was conducted. In one study, 20% of patients had pruritus, which was associated with vitiligo and which could not be attributed to other comorbidities like diabetes or thyroid disease. (44) Pruritus thus seems to be a common finding in vitiligo patients. Ongenae et al. reported the same findings as those of our cohort for Question 2, but differed for Question 1, where their patients with vitiligo had a very low score for Question 1 (symptoms), however, some patients reported itchy or burning skin when exposed to the sun. (5)

A family history of vitiligo was mentioned in eighteen (n=18, 18.95%) patients. This is higher than 11/48 (23%) reported by Kostopoulou et al. in France. (40) More studies are needed to assess whether or not a family history of vitiligo is common among African rather than Caucasian patients, as a majority of our patients were identified as black. Family history of vitiligo or duration of the disease were not significantly associated with DLQI scores in our study. This is the same as findings reported by Ongenaes et al. in Belgium. Our findings are partly contested by finding of Radtke et al., where increasing duration of the disease led to a higher impairment in QoL. Radtke et al. did not test the relationship between the DLQI score and family history of vitiligo. (5, 41)

Although it was not of significance statistically, the mean DLQI scores increased with the skin contrast, with those identified as white having the least (8), those identified as black and colored having the highest (10.06 and 10.58, respectively), and those identified as Indian with 9.5. The low number of white and Indian patients may be the explanation for the absence of a statistically significant difference when comparing the DLQI scores in different races. Studies have suggested that the more the skin contrast between pigmented and depigmented skin, the greater the QoL impairment.(39)

Exposed areas like the face (n=58, 61.05%), hands (n=49, 51.58%), legs (n=49, 51.58%) and neck (n=40, 42.11%), were frequently affected. In line with various other studies, visibility of the lesion did not significantly correlate with DLQI scores in our study. This contrasts with the findings of Wong and Baba in Malaysia. However, it has been reported several times that cosmetic camouflage can help in improving QoL in chronic skin diseases. (6, 36, 42, 45, 46)

We did not find a significant relationship when comparing increasing body surface area with vitiligo lesions and DLQI scores ( $p > 0.05$ ). However, several authors reported varying results

when investigating effect of the size of body surface affected on QoL of their respondents. (5, 7, 38, 41, 43)

As previously reported by Wong and Bab in Malaysia, duration of disease did not statistically correlate with DLQI scores in our study. This contrasts findings reported in India, as well as the findings of the study by Radtke et al. in Germany, where a much higher limitation in their patients' QoL was observed. (6, 7, 41)

Patients who were on phototherapy treatment did not show improved DLQI scores compared to those who were not on phototherapy. This differs from the findings of Wong et al., where a significant relationship was observed between DLQI scores and phototherapy. This may be explained by the possibility of poor response to phototherapy treatment in our cohort that may have a negative psychological influence on our patients. (6) Studies have shown that a good response to medical treatment of vitiligo as well as psychological therapy improves DLQI scores. (7, 47)

## 4.2 CONCLUSION

This was a cross-sectional prospective study done at tertiary public hospitals, therefore may not show the real impact of vitiligo on the QoL of all South Africans with the condition. Most of our patients were referred, probably the most affected and difficult to treat at lower health facilities, with a high average Dermatology Life Quality Index score.

Our study has demonstrated that vitiligo moderately affects the QoL of adult South Africans. In diseases like vitiligo, which are very difficult to treat, with limited treatment options and adversely affecting QoL of patients, this would provide an argument for psychological management suggestions, such as the establishment of psychodermatology clinics at our referral hospitals. This would help patients' management both psychologically and physically. It was well-demonstrated by Parsad D et al. that there is a low response to a given treatment option in patients with higher DLQI scores, therefore, addressing psychosocial issues may improve treatment outcomes. (7)

This will equip our training dermatologists (registrars) with the knowledge to manage most skin disorders affecting the QoL of patients more effectively. Moreover, training of dermatologists in other treatment options like skin grafting and needling as well as availing these options to dermatologists would be of similar value. It has been shown by Bin Saif et al. that vitiligo not only affects the QoL of the patient in particular, but also affects the QoL of the entire family. (32)

Though vitiligo is an asymptomatic disease, our study has alongside other studies well demonstrated that vitiligo affects the QoL of patients, and that therefore, psychological factors ought to be taken into more serious consideration when managing these patients.

## APPENDICES

### APPENDIX A. Dermatology Life Quality Index Questionnaire

|    |                                                                                                                                                                                                                 |                                                  |                                                                                                                                              |                                       |
|----|-----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|--------------------------------------------------|----------------------------------------------------------------------------------------------------------------------------------------------|---------------------------------------|
| 1  | Over the last week, how <b>itchy, sore, painful</b> or <b>stinging</b> has your skin been?                                                                                                                      | Very much<br>A lot<br>A little<br>Not at all     | <input type="checkbox"/><br><input type="checkbox"/><br><input type="checkbox"/><br><input type="checkbox"/>                                 |                                       |
| 2  | Over the last week, how <b>embarrassed</b> or <b>self-conscious</b> have you been because of your skin?                                                                                                         | Very much<br>A lot<br>A little<br>Not at all     | <input type="checkbox"/><br><input type="checkbox"/><br><input type="checkbox"/><br><input type="checkbox"/>                                 |                                       |
| 3  | Over the last week, how much has your skin interfered with your going <b>Shopping</b> or looking after your <b>home</b> or <b>garden</b> ?                                                                      | Very much<br>A lot<br>A little<br>Not at all     | <input type="checkbox"/><br><input type="checkbox"/><br><input type="checkbox"/><br><input type="checkbox"/>                                 | Not relevant <input type="checkbox"/> |
| 4  | Over the last week, how much has your skin influenced the <b>clothes</b> you wear?                                                                                                                              | Very much<br>A lot<br>A little<br>Not at all     | <input type="checkbox"/><br><input type="checkbox"/><br><input type="checkbox"/><br><input type="checkbox"/>                                 | Not relevant <input type="checkbox"/> |
| 5  | Over the last week, how much has your skin affected any <b>social</b> or <b>leisure</b> activities?                                                                                                             | Very much<br>A lot<br>A little<br>Not at all     | <input type="checkbox"/><br><input type="checkbox"/><br><input type="checkbox"/><br><input type="checkbox"/>                                 | Not relevant <input type="checkbox"/> |
| 6  | Over the last week, how much has your skin made it difficult for you to do any <b>sport</b> ?                                                                                                                   | Very much<br>A lot<br>A little<br>Not at all     | <input type="checkbox"/><br><input type="checkbox"/><br><input type="checkbox"/><br><input type="checkbox"/>                                 | Not relevant <input type="checkbox"/> |
| 7  | Over the last week, has your skin prevented you from <b>working</b> or <b>studying</b> ?<br>Yes<br>No<br>If "No", over the last week, how much has your skin been a problem at <b>Work</b> or <b>studying</b> ? | Yes<br>No<br><br>A lot<br>A little<br>Not at all | <input type="checkbox"/><br><input type="checkbox"/><br><br><input type="checkbox"/><br><input type="checkbox"/><br><input type="checkbox"/> | Not relevant <input type="checkbox"/> |
| 8  | Over the last week, how much has your skin created problems with your <b>partner</b> or any of your <b>close friends</b> or <b>relatives</b> ?                                                                  | Very much<br>A lot<br>A little<br>Not at all     | <input type="checkbox"/><br><input type="checkbox"/><br><input type="checkbox"/><br><input type="checkbox"/>                                 | Not relevant <input type="checkbox"/> |
| 9  | Over the last week, how much has your skin caused any <b>sexual difficulties</b> ?                                                                                                                              | Very much<br>A lot<br>A little<br>Not at all     | <input type="checkbox"/><br><input type="checkbox"/><br><input type="checkbox"/><br><input type="checkbox"/>                                 | Not relevant <input type="checkbox"/> |
| 10 | Over the last week, how much of a problem has the <b>treatment</b> for your skin been, for example by making your home messy, or by taking up time?                                                             | Very much<br>A lot<br>A little<br>Not at all     | <input type="checkbox"/><br><input type="checkbox"/><br><input type="checkbox"/><br><input type="checkbox"/>                                 | Not relevant <input type="checkbox"/> |

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## APPENDIX B. Data collection sheet

1. Unique patient ID:

2. Date

### Demographic data

3. Age:

4. Gender: ☐ Male ☐ Female

5. Race: ☐ White ☐ Black ☐ Coloured ☐ Indian ☐ Others

6. Nationality:

7. Marital status: ☐ Single ☐ Married ☐ Divorced

8. Occupation:

### Clinical characteristics

9. Age at onset:

10. Duration of the disease:

11. Family history of vitiligo: ☐ Yes ☐ No

12. Localisation of disease:

☐ Legs ☐ Neck ☐ Face ☐ Hands  
13. ☐ Feet ☐ Trunk ☐ Genitals ☐ Breast

14. Body surface area involved:

15. Treatment modalities: ☐ Phototherapy  
☐ Topical steroids  
☐ Others

16. Type of vitiligo: ☐ Localised

☐ Segmental ☐ Generalised ☐ Acrofacial  
☐ Mucosa ☐ Universal

## **APPENDIX C. Patient's Informed Consent**

### **QUALITY OF LIFE AMONG VITILIGO PATIENTS ATTENDING DERMATOLOGY OUTPATIENT CLINICS IN JOHANNESBURG**

**Greetings and introduction:** Good morning/good afternoon.

My name is Dr. Elisah Agaba. I am specialising in skin diseases at the University of Witwatersrand. I am interested in finding out how much this condition (vitiligo) has affected your life. This will be achieved by doing a research study. Research is a process of discovering the answer to a question.

**Invitation to take part in the study:** I hereby invite you to take part in the study entitled 'Quality of life among vitiligo patients attending Dermatology outpatient clinics in Johannesburg'.

**What is involved in the study:** We are interested in finding out how much this condition (vitiligo) has affected the activities of daily living of our patients, including yourself. If you accept to participate, you will answer 10 questions for us. This will take you less than fifteen minutes. I will get some general information from your hospital file, such as age, marital status, etc. and information related to your treatment, then examine you. All our patients attending our dermatology outpatient clinics either for the first time or as follow-up with the same condition during the study period will be requested to participate in the study.

**Voluntary participation:** It is your choice whether or not to accept or refuse to participate or pull-out from this research anytime, or as the need arises. You will not be penalised or lose benefits because you have refused or withdrawn from this research. You will continue receiving treatment as you should.

**Has the research received ethics approval:** Permission to undertake this research has been received from the University of Witwatersrand Ethics Committee and the CEO of Charlotte Maxeke Johannesburg Academic Hospital/Chris Hani Baragwanath Academic Hospital/Helen Joseph Hospital.

**Confidentiality:** All efforts will be taken to keep your private information as confidential as possible. Collected information will be managed anonymously, and given research numbers and will not bear your names. Only the investigators will have access to the data.

**Contact details:** For further information, queries and reporting of study related events,

Professor Deepak Modi can be contacted any time on the following numbers:

Mobile: 0834577090, Office: 0114883644

Alternatively: Dr. Elisah Agaba

Mobile: 0717873679

**Informed consent to be signed by the patient**

I, the undersigned. Mr./Ms./Mrs.....

Hereby testify that the procedure and the reason for this research was well explained to me by Dr.....I furthermore confirm my understanding that my taking part in this research is totally of my own will and that I can easily withdraw consent at any time.

Patient's Surname.....Signature

Date:

Investigator's Name.....Signature

Date:



**UNIVERSITY OF THE WITWATERSRAND, JOHANNESBURG**  
**Division of the Deputy Registrar (Research)**

**HUMAN RESEARCH ETHICS COMMITTEE (MEDICAL)**  
R14/49 Dr Elisah Agba

**CLEARANCE CERTIFICATE**

**M121031**

**PROJECT**

Quality of Life Among Vitiligo Patients Attending  
Dermatology Out-Patient Clinics in  
Johannesburg

**INVESTIGATORS**

Dr Elisah Agba.

**DEPARTMENT**

Department of Internal Medicine/Dermatology

**DATE CONSIDERED**

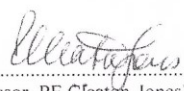
26/10/2012

**DECISION OF THE COMMITTEE\***

Approved unconditionally

**Unless otherwise specified this ethical clearance is valid for 5 years and may be renewed upon application.**

**DATE** 18/12/2012

**CHAIRPERSON**   
(Professor PE Cleaton-Jones)

\*Guidelines for written 'informed consent' attached where applicable  
cc: Supervisor : Dr D Modi

**DECLARATION OF INVESTIGATOR(S)**

To be completed in duplicate and **ONE COPY** returned to the Secretary at Room 10004, 10th Floor, Senate House, University.

I/We fully understand the conditions under which I am/we are authorized to carry out the abovementioned research and I/we guarantee to ensure compliance with these conditions. Should any departure to be contemplated from the research procedure as approved I/we undertake to resubmit the protocol to the Committee. **I agree to a completion of a yearly progress report.**

**PLEASE QUOTE THE PROTOCOL NUMBER IN ALL ENQUIRIES...**

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