

Assessment of quality of life in Indian patients with vitiligo, an observational study

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ABSTRACT

Background: Vitiligo is the most common hypopigmentary disorder. In India, the incidence of vitiligo is 0.25-2.5%. It considerably influences the patient's quality-of-life (QoL) and psychological well-being.

Methods: A prospective, observational study was conducted from April 2016 to September 2016 in dermatology outpatient department. Patients clinical characteristic were noted and Quality of life was assessed by using Vitiligo Quality of Life Questionnaires [VQLQ]. During item development, none of the questions were changed according to the results of cognitive and understand ability testing. The scale consisted of 25 questions. The answer to each question was scored as 'never = 1', 'sometimes = 2', 'often = 3' and 'all the time = 4', so the total score ranged between 25 and 100. Higher scores represented more severely impaired quality of life.

Results: We enrolled 78 Vitiligo patients who were attending dermatology department for phototherapy. Out of them 53 were female. Mean age was 37.12 ± 12.270 . Most common age group was 31-40 years. Mean VLQL score 40.92 ± 6.081 . Patients were divided based on VQLQ score in Moderate (50-75) and Low score group (25-50). Vitiligo patients presented with symptoms of pain, irritation and itching ($P < 0.0001$). Vitiligo patients when assessed for feeling domain were significantly embarrassed for their overall look and appearance. ($P < 0.0001$). When Personal relationship domain was analysed physical contact was a major concern ($P < 0.002$). Patients suffering from Vitiligo were significantly worried about spread of vitiligo and occurrence of cancer ($P < 0.0001$). Therapy for Vitiligo was time consuming time and was a work place challenge for the patients ($P < 0.0001$). The reliability of VQLQ in our study was Cronbach's α coefficient was 0.876.

Conclusions: QoL impairment was relatively high in vitiligo patients. Medical intervention and counselling should focus to improve feelings, personal relationship, anxiety, school/work, leisure and symptom domains.

Keywords: Quality of life, Vitiligo, VQLQ

INTRODUCTION

Vitiligo is a common depigmenting skin disorder characterized by acquired, idiopathic, progressive, circumscribed hypomelanosis of the skin and hair. It occurs worldwide, with an incidence of 0.5% to 2.0%.¹

Vitiligo is disfiguring in all races but particularly more so in dark skinned people because of strong contrast.² Vitiligo

may entail significant psychosocial consequences. Vitiligo is a social stigma and is associated with a decreased quality of life, especially when lesions are located over the face; thus, it may affect the quality of social and personal life depending on the patient's perception.³

In India and perhaps elsewhere also men, women and children with vitiligo face severe psychological and social problems. Many vitiligo patients felt distressed and

stigmatized by their condition. They attract undue attention from the general public sometimes whispered comments, antagonism and ostracism. The self-image of the vitiligo patients drops considerably and may lead to depression. These patients often develop negative feelings about it, which are reinforced by their experiences over a number of years. Most patients of vitiligo report feelings of embarrassment, which can lead to a low self-esteem and social isolation.^{2,4} Vitiligo lesions over face may be particularly embarrassing and the frustration of resistant lesions over exposed part of hands and feet can lead to anger and disillusionment. Particularly in teenagers, mood disturbances including irritability and depression are common. Patients with vitiligo are very sensitive to the way other perceives them and they will often withdraw, because they anticipate being rejected. Sometimes, strangers and even close friends can make extremely hurtful and humiliating comments. The impact of such factors is profound subjecting them to emotional distress, interference with their employment, or use tension-reducing, oblivion-producing substances such as alcohol.⁵ Severe depression has been known to lead to suicide attempts.⁶

Quality of life (QoL) is a multidimensional index of the different social, behaviour and cultural factors. Different tools were created for measuring QoL focusing on different conditions and diseases.⁷⁻¹¹

The purpose of this study is to evaluate the burden of Vitiligo on the quality of life of Vitiligo patients using Vitiligo specific life quality questionnaire developed by Senol et al.¹¹

The objective of the study was to assess the impact of the disease on the quality of life of patients suffering from vitiligo.

METHODS

After the approval of study protocol by Institutional Review Board, a prospective observational study was carried out between April 2016 to June 2016 i.e. 3 months at tertiary care teaching hospital Dermatology Outpatient Department. Vitiligo patients aged more than 18 to 70 years old were included in the study. Informed consent was obtained from all the patients and confidentiality of data was maintained. Unwilling patients, patients below the age of 18 years were excluded from the study. We used Vitiligo specific life quality questionnaire developed by Senol et al.¹¹

The questionnaire was classified into 6 headings (Domain):

- Feelings (questions 2,3,4,6,12,13,18,19)
- Personal relationships (questions 20,21,22,25)
- Anxiety (questions 8,10,11,23)
- Work and School (questions 5,7,17)
- Leisure (questions 14,15,16,24)

- Symptom (question 1,9).

During item development, none of the questions were changed according to the results of cognitive and understandability testing. The scale consisted of 25 questions. The answer to each question was scored as 'never = 1', 'sometimes = 2', 'often = 3' and 'all the time = 4', The VQLQ score is calculated by summing the scores of all the questions, resulting in a maximum of 100 and a minimum of 25. The higher the VQLQ score, the more is the quality of life impaired.

Data were expressed as mean and standard deviation. Comparisons were made using Student's t-tests, and the level of significance was set at $P < 0.05$.

Statistical analysis

Data was entered into Microsoft Excel 2016®. SPSS® software (version. 21.0 IBM Corporation, California,) was used for statistical analyses. The descriptive analysis was presented in tables as mean and SD for numeric data and frequency (n) and percentage (%) for categorical data. Fisher's exact test was used to assess gender variation. Reliability of VQLQ was assessed using Cronbach α .

RESULTS

We enrolled 78 Vitiligo patients who attended dermatology department for phototherapy, out of which 53 were female patients. Most common age group in our study was 31-40 yrs (Figure 1). Mean age was 37.12 ± 12.27 yrs.

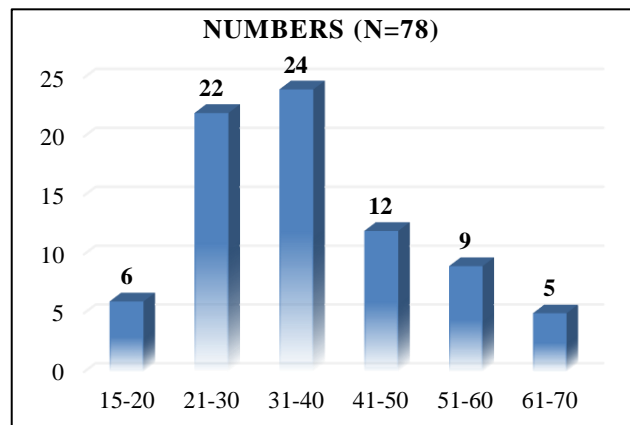


Figure 1: Age wise distribution.

Clinical characteristics: Most commonly involved area was trunk region (32.2%) as shown in Figure 2.

Vitiligo quality of life questionnaire (VQLQ)

VQLQ score Mean \pm SD: 40.92 ± 6.081 . Highest score was 55 and Lowest score was 27. Severity was increased as score increased. We divided total number of patients into

two groups Mildly affected group (25-50) and Moderately affected group (51-75).

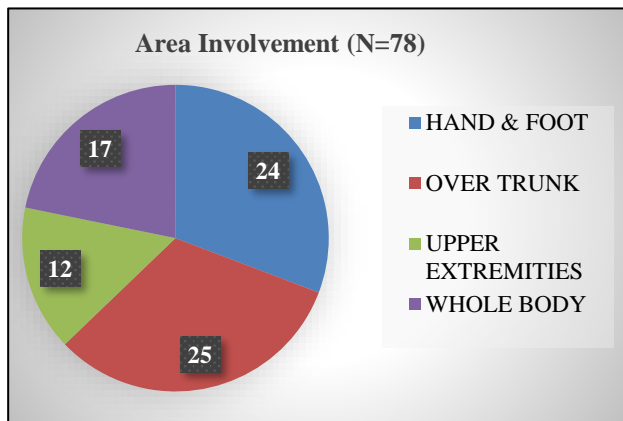


Figure 2: Area involvement.

Vitiligo patients when assessed for feeling domain they were significantly embarrassed for their overall look appearance. (P <0.0001) (Table 1).

Table 1: Feeling domain analysis.

Feelings	Mild	Moderate	P-value
Make up (Q4)	1.54	2.57	0.0001
Felt uncomfortable abt ques (Q18)	1.96	2.86	0.0001
Embarrassed d/t appearance (Q2)	2.30	3.14	0.0015
Uncomfortable looking into mirror (Q12)	2.48	3.86	0.0001
Uneasy about staring (Q3)	1.58	2.14	0.0107
Stayed away from crowded areas (Q13)	1.11	1.14	0.835
Self-esteem (Q6)	2.28	2.86	0.0131
Isolated (Q19)	1.08	1.86	0.0001

(P-value <0.05 was taken as significant value)

When Personal relationship domain was analysed physical contact was major concern (P <0.002) (Table 2).

Table 2: Personal relationship domain analysis.

Personal relationship	Mild	Moderate	P-value
Intimacy (Q25)	1.00	1.00	-
Partner Quarrel (Q20)	1.03	1.00	0.6379
Family issues (Q22)	1.21	1.00	0.183
Avoid Physical contacts (Q21)	1.03	1.29	0.0026

(P-value <0.05 was taken as significant value)

In Vitiligo patients, they were significantly worried about spread of vitiligo and occurrence of cancer (P<0.0001) (Table 3).

Table 3: Anxiety domain analysis.

Anxiety	Mild	Moderate	P-value
Concerns to spread (Q8)	1.89	2.71	0.0001
Anxiety over vitiligo permanent (Q10)	2.72	3.71	0.079
Inheritance (Q11)	1.58	1.43	0.4513
Personal items sharing (Q23)	1.03	1.00	0.6379

(P-value <0.05 was taken as significant value)

Vitiligo is consuming time and its work place challenge to the patients (P <0.0001) (Table 4).

Table 4: School/work domain analysis.

School/work	Mild	Moderate	P-value
Covering clothes(Q5)	1.01	1.29	-
Concealment (Q7)	1.03	1.86	0.0001
Challenges faced (Q17)	1.01	1.43	0.0001

(P-value <0.05 was taken as significant value)

Vitiligo patients felt that disease consumes time, money at the cost of time spend in hobbies and with family (Table 5).

Table 5: Leisure domain analysis.

Leisure	Mild	Moderate	P-value
Vacation plans (Q15)	1.00	1.00	-
Free time, Ur hobbies (Q16)	1.00	1.00	-
Sun exposure/ Protection (Q14)	2.44	3.14	0.0017
Compliance (Q24)	2.46	3.43	0.0006

(P-value <0.05 was taken as significant value)

Vitiligo patients presented with symptoms of pain, irritation and itching (P<0.0001) (Table 6).

The reliability of VQLQ in our study was Cronbach's α coefficient was 0.876 considered as good. QoL impairment was relatively high in vitiligo patients.

Table 6: Symptom domain analysis.

Symptom	Mild	Moderate	P-value
Pain, Irritation (Q1)	2.69	3.71	0.0001
Skin cancer (Q9)	1.32	2.14	0.0001

DISCUSSION

Vitiligo is an important skin disease having major impact on the quality of life of patients suffering from vitiligo. Appearance of skin condition is important for an individual self-image, and any pathological alteration can have psychological consequences.

So, our study was aimed to assess the impact of Vitiligo on the quality of life of patients.

Demographic characteristics

Most common age group in our study was between 31-40 yrs that was similar to a study done by Hedayat K et al.¹² This suggests that vitiligo is highly prevalent disease below age of 40 years.

There was female preponderance in our study which is also seen in other studies.

Although vitiligo affects both sexes equally, most of the studies show a female preponderance.¹³⁻¹⁵ The cause of female preponderance presenting in dermatology clinic is probably because of greater cosmetic awareness and the impact of the disease on their social life.¹⁶ This is due to autoimmune nature of the disease, which are more prevalent in females.

The reasons for the high prevalence in women are unknown, but circumstantial evidence links autoimmune diseases with preceding infections. Sex hormones may further amplify this hyperimmune response to infection in susceptible persons, which leads to an increased prevalence of autoimmune diseases in women.¹⁷ People suffering from certain autoimmune disease such as hyperthyroidism are more likely to get vitiligo than people who don't have any autoimmune disease. Scientists don't know why vitiligo is connected with these diseases. However, most people with vitiligo have no other autoimmune disease.¹⁸

Area involved

In our study, most commonly involved area was over trunk region (32.2%) followed by hand and foot region.

Psychological and social impact using VQLQ

In our study Mean VQLQ score was 40.92±6.08 which showed mild deterioration of quality of life. Highest score was 55 and Lowest score was 27. Patients were divided based on VQLQ score in Moderate (50-75) and Low score group (25-50). No. of patients belonging to moderate group was 5 patients and in low score group was 73 patients.

Feeling domain

Vitiligo patients when assessed for feeling domain, were significantly embarrassed for their overall look appearance. Patients were more psychologically concerned about their appearance, they had low self-esteem and they often felt uncomfortable when they were asked about their disease. (P<0.001). Similar results were shown in Porter et al, Prasad et al, Mattoo et al, Finlay et al studies.^{2,4,19,20} Vitiligo patients were having negative beliefs about their overall look. Concern regarding their

looking different from others and getting a stare was of a concern in patients suffering from vitiligo. (P<0.05). Suffering from the disease did not make them stay away from crowded areas like public transportation, shopping centres, etc. (P=0.835).

Personal relationship domain

When Personal relationship domain was analysed physical contact was major concern (P <0.05). This result was similar to previous study done by Porter et al, which reported 23% decline in physical contact.²¹ Vitiligo patients reported to have no issues with their partner and family issues with P=0.638 and p=0.183, respectively.

Anxiety domain

VQLQ evaluated domain of anxiety also, in our study patients were anxious for the spread of the lesions to other body parts and its permanent complications, (P<0.05) but statistically no difference was found in high score group and low score group for inheritance to their children and article sharing. This finding was also reciprocated as in Tunisia study and Belgian study.^{22,23} Vitiligo patients were apprehensive due to their lesions on body parts. They were never afraid of vitiligo being permanent (p=0.079) and never worried about inheritance of vitiligo to their children (p=0.451). Patients of vitiligo never felt uneasy about sharing personal items with the household members. (P=0.638).

School/ work domain

Vitiligo is consuming time for clothing to cover lesions and it is considered as a work place challenge to the patients (P <0.005). This finding was also reciprocated in Porter et al studies that in an attempt to hide their vitiligo lesions, many patients wore adapted clothing and applied large quantities of cosmetics.²⁴⁻²⁶

Leisure domain

In our study, most of the patients felt that disease consumes time, money at the cost of time spent in hobbies and with family. Also, patients felt confined to home and avoided sun exposure. (P<0.05) Patients of Vitiligo had lesser free time for enjoyment.²⁷

Symptom domain

Vitiligo patients presented with symptoms of pain, irritation and itching (P<0.0001). A similar study of Linthorst Homan et al, reported pruritus in 20% of vitiligo patients.²⁸ Patients of Vitiligo felt uneasiness due to symptoms. Melanin pigment produced by melanocytes used to absorb ultraviolet light (UV) and thus prevent DNA damage. Melanin also works as a Scavenger of free radicals in human body. Hence lack of epidermal melanin increases susceptibility to skin cancers and is an indicator of aging skin.¹⁸

Reliability of VQLQ

The reliability of VQLQ in our study was Cronbach's α coefficient was 0.876 which is considered as good. QoL impairment was relatively high in vitiligo patients.

This was a first study of its kind done at our set up which evaluated impact of vitiligo on quality of life. The patient Quality of Life (QoL) was measured at the time they were presented for treatment at dermatology outpatient department. They were receiving standard treatment like PUVA, Narrow band UV-A, UV-B. The authors write the conclusion feeling domain was most severely affected in comparison to personal relationship and leisure domain.

The limitation to this study is that VLQI could be applied to larger patient groups involving various severities of the disease all skin types can increase its value as a scale. The first step in helping vitiligo patients who felt isolated and who isolate themselves from the community is to understand how severely their quality of life is impaired. We could not measure Quality of Life with respect to Treatment and Improvement. Comparison with normal population was not done. Compliance for regular long-term visits for PUVA/narrow band UVB therapy, side effects of immunosuppressive therapies, long term risk of photoaging and carcinogenesis with phototherapy are other limitations for vitiligo patients. The VLQI, which has been developed for this purpose, has been proven to better reflect the quality of life of vitiligo patients than the DLQI and to be more commonly preferred by them. The VLQI is ready for use in our clinical practice and can be used in further epidemiologic studies where temporal change in the scores during treatment should be observed to further test sensitivity.

CONCLUSION

In vitiligo, Counselling can help improve body image, self-esteem, and quality of life of patients with vitiligo.²⁹ There are two types of strategies to counter vitiligo psycho-social impact. Behavioural strategies focused on the problems and involved avoidance of situations and concealment of the vitiligo lesions. These though helpful in the short term, caused restriction in activities. The cognitive strategies focused on the emotions. It dealt with modifying the patients feeling of being different and their interpretation of others' behaviour. With this, a strategy of acceptance of difference was attained over a period, which was facilitated by social support; however, it was difficult to maintain this strategy.³⁰ In an attempt to hide their vitiligo lesions, many patients wore adapted clothing and applied large quantities of cosmetics.²⁴⁻²⁶ There is a need for accessible, accurate, community-based education about the natural history of vitiligo, the effectiveness of treatments and its expected duration. The provision of such information facilitates therapeutic selection by the patient, enhancing their understanding of treatment options and influencing the public attitude towards this disease.

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Conflict of interest: None declared

Ethical approval: The study was approved by the Institutional Ethics Committee

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ANNEXURE-I

VLQI (Vitiligo Life Quality Index).

Please answer the questions below in light of the last week.

Que No.	Questions
1	Have you had pain, irritation, or itching due to vitiligo?
2	Have you felt embarrassed or insecure about the appearance of your vitiligo?
3	Have you felt uneasy about others staring at you because of Vitiligo?
4	Have you used make-up to conceal vitiligo?
5	Have you picked out clothing specifically to cover up vitiligo?
6	Has vitiligo reduced your self-esteem?
7	Have you not wanted others to see your body due to vitiligo?
8	Have you had concerns about vitiligo spreading to other parts of your body?
9	Have you had concerns about getting skin cancer because of Vitiligo?
10	Have you had anxiety over vitiligo being permanent?
11	Have you worried that your children might inherit vitiligo from you?
12	Have you felt uncomfortable looking in the mirror due to vitiligo?
13	Have you stayed away from crowded areas (public transportation, shopping centers, etc.) due to your vitiligo?
14	Have you had difficulty with sun exposure or protection due to your vitiligo?
15	Has vitiligo affected your vacation plans?
16	Has vitiligo had an impact on what you do on your free time, your activities, and hobbies?
17	Have you had any challenges at school or work due to vitiligo?
18	Have you felt uncomfortable with questions asked about your vitiligo and the explanations you had to make?
19	Have you felt isolated or been made fun of due to vitiligo?
20	Have you had issues with your partner due to vitiligo?
21	Have you avoided physical contact with others (shake hands, give hugs or kisses, etc.) because of vitiligo?
22	Have you had family issues due to vitiligo?
23	Have you felt uneasy about sharing personal items with the household due to vitiligo?
24	Have you had difficulty keeping up with vitiligo therapy (spending too much time or money, applying medicine, etc.)?
25	Have you had problems in your sexual relations because of vitiligo?