

Screening for Psychological Burden of Vitiligo Using Vitiligo Impact Scale

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ABSTRACT

Background: Chronic skin diseases conditions have been well reported to affect a patient's quality of life on multiple dimensions, including the psychosocial domain. Patients can suffer from lowered self-esteem, anxiety, or depression. The assessment of the psychosocial impact of skin disease on a patient could facilitate the treatment plane and procedure to be carried out by the dermatologists to deal with the disease. **Aim:** the aim of this study was to assess the psychological burden of vitiligo using Vitiligo Impact Patient scale (VIPs). **Materials and methods:** A descriptive study was conducted on 60 vitiligo patients. All patients were assessed using Vitiligo Impact Scale. Data collected were analyzed using SPSS software. **Results:** Among the studied patients, 68.3% were females. Almost half of the patients (43.3%) were single, whilst only 28.3% were married. Half of the patients had generalized vitiligo, and 51.7% had vitiligo on their faces. According to the VIP, the vast majority of patients (56.7%) were moderately affected, one fourth (25%) of them were highly affected, and only 8.5% were slightly affected. There was a statistically significant correlation between the VIP score and patient's age, sex, disease duration, marital status, vitiligo on the face, and percentage of the involved area. **Conclusions:** Vitiligo is considered as a major psychological impact on patients. This psychological impact is significantly correlated with patient's age, sex, duration of disease, marital status, the presence of vitiligo in the face, and percentage of area involved. However, there is no significant correlation between the family history of vitiligo, level of education and psychological impact of vitiligo.

Keywords: Psychological burden, vitiligo, vitiligo impact score.

INTRODUCTION

Chronic skin diseases conditions have been well reported to affect a patient's quality of life (QOL) on multiple dimensions, including the psychosocial domain. Because many skin conditions are commonly associated with social stigmatization, patients can suffer from lowered self-esteem, anxiety, or depression. The assessment of the psychosocial impact of skin disease on a patient can help in the direction of the dermatologists' in the treatment goals of the disease^[1, 2]. Vitiligo is the most common depigmenting disorder, with a prevalence of approximately 1% in the world population^[3]. In some countries, vitiligo is still confused with leprosy with a considerable social stigma. Indeed, many studies have documented significant effects of vitiligo on health-related quality of life (QoL), using validated generic and dermatology-specific health-related QoL scales^[3, 4].

The concept of "burden" has played an increasingly important role in evaluating the care of chronic diseases, and more specifically skin diseases^[5]. The notion of global burden was introduced by the WHO and is useful in quantifying the health of a population and determining priorities of action in the public health domain^[6, 7]. The notion of burden has recently been extended to individuals and their families, to assess disability in a broad sense (psychological, social, economic, and physical), related to various diseases including

psoriasis^[8] and many various chronic skin diseases. Indeed, in a recent paper,

Ramam et al.^[9] estimated the global burden of 15 skin diseases in 187 countries. This global estimation includes social integration, emotional state, everyday-life organization, and the use of medical resources including consultations and medication. To the best of our knowledge, there are few studies available for assessing the burden experienced by individuals affected by vitiligo, although there is a need for conducting such a study that would be beneficial for clinicians and patients alike and which would also allow for an evaluation of the impact of vitiligo treatment. Therefore, the aim of this study was to assess the psychological burden of vitiligo using Vitiligo Impact Patient scale (VIPs).

MATERIALS AND METHODS

A descriptive study research design was used to assess the psychological burden of vitiligo. The study was conducted on 60 vitiligo patients attending to the dermatology outpatients' clinic at Alnoor clinic, Alzahir clinic and Hera'a clinic for a period of three months, commencing from July 2017 To September 2017. All included vitiligo patients were assessed using Vitiligo Impact Scale. This tool was adapted from **Kostopoulou et al.**^[10], after reviewing of the current related literature. The tool was translated into the Arabic language by the researcher to ensure that all patients fully

understand each question. It consisted of two parts. part one contained questions related to the patient's bio-sociodemographic data as patient's age, sex, marital status, duration of disease, and family history of vitiligo. Part two included 27 questions to assess the psychological burden of vitiligo. Patients from 20 to 50 years of age and free from other chronic skin diseases were included in the study. Each item in part two was coded according to the frequency of experiencing that psychological feeling as follow: (Often=4, Sometimes=3, Rarely=2, Never=1, and Not applicable=0).

After data collection, it was coded and entered into the computer. The data was checked for correction of any errors during data entry. SPSS program version 20.0 was used for data presentation (tables, graphs, and mathematical presentations) and statistical analysis. Number and percent were used for presenting qualitative variables. Mean and mean percent were carried out for the quantitative variables. The 0.05% level of significance was used. Fissure Exact test was done to determine the correlations. Correlations were calculated as Less than or equal 0.05 was considered significant correlation and Less than or equal 0.01 was considered highly significant correlation. Scoring system for the degree of psychological burden was categorized as follows: (Highly affected: 85-108, moderately affected: 60-84, slightly affected: 35-59, and Not affected at all: less than 35).

RESULTS

The study was conducted on 80 patients. Table 1 summarizes the frequency distribution of studied vitiligo patients according to bio-sociodemographic characteristics. Approximately more than half of patients (51.7%) were less than 25 years of age. Regarding sex, the table showed that more than two thirds (68.3%) of patients were male. In relation to marital status the same table revealed that more than two fifth (43.3%) of patients were single, and less than one third (28.3%) were married. As regards level of education, the highest percentage (38.3%) of patient were illiterate followed by primary education (33.3%), secondary education (16.7%) and the lowest percentage (11.7%) were for university education. Concerning the duration of disease, about two third (61.6%) of patients were have vitiligo for more than 5 years. Regarding type of disease, more than half of patients (50%) have localized disease and two fifth of patient (41.7%) have generalized disease. In relation to presence of vitiligo in face, it was noticed that more than half of patients (51.7%) have vitiligo in face. As for family

history of vitiligo, the table showed that more than two thirds of patients (65%) have positive family history of vitiligo. According to percentage of area involved, the table revealed that less than half of patients (45%) have more than 75% of total body surface area affected followed by one third of patients (36.7%) have from 26%- 75% of total body surface area affected.

Figure 1 demonstrates the frequency distribution of patients according to the total vitiligo impact scale. The results revealed that more than half of patients (56.7%) were moderately affected, followed by one quarter of patients (25%) were highly affected while the lowest percentage of patients (8.3%) were slightly affected. Detailed distribution of studied patients according to vitiligo impact scale points is demonstrated in table 2. The results showed that, there were a statistical significant correlation between vitiligo as a disease and the patient's psychological status.

The relation between vitiligo impact and patients' bio-sociodemographic data was studied (table 3). Results revealed that there was a significant correlation between psychological impact of vitiligo and patient's age, sex, duration of disease, marital status, presence of vitiligo in face, and percentage of area involved, while there was insignificant correlation between family history of vitiligo, level of education and psychological impact of vitiligo.

Table 1: Frequency distribution of the studied vitiligo patients according to their bio-sociodemographic characteristics

Patients' bio-sociodemographic characteristics	N	%
Age		
Less than 25 years of age	31	51.7
More than 25 years of age	29	48.3
Sex		
Male	41	68.3
Female	19	31.7
Marital status		
Single	26	43.3
Married	17	28.3
Widow	10	16.7
Divorced	7	11.7
Level of education		
Illiterate	23	38.3
Primary	20	33.3
Secondary	10	16.7
University	7	11.7

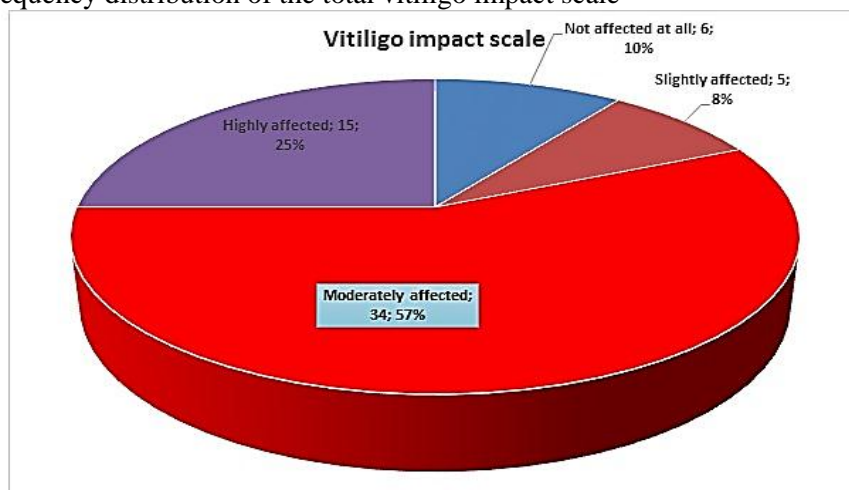
Table 2: frequency distribution of the total vitiligo impact scale

		Data				Wt	%	Chi-square	
		Never	Rarely	Sometimes	Often			X ²	P-value
1. Do you have any problems in wearing your choice of clothes?	N	44	9	5	2	85	35.42	76.400	0.001
	%	73.3%	15.0%	8.3%	3.3%				
2. Do other people feel that this disease spreads by touch?	N	21	9	14	16	145	60.42	4.933	0.177
	%	35.0%	15.0%	23.3%	26.7%				
3. Do you think this disease is not curable?	N	11	7	7	35	186	77.50	36.267	0.001
	%	18.3%	11.7%	11.7%	58.3%				
4. Do you change your doctor?	N	13	1	10	36	189	78.75	44.400	0.001
	%	21.7%	1.7%	16.7%	60.0%				
5. Do suggestions and advice from others about the disease bother you?	N	9	13	10	28	177	73.75	15.600	0.001
	%	15.0%	21.7%	16.7%	46.7%				
6. Do you feel difficulties in adhering to treatment?	N	8	36	12	4	132	55.00	41.333	0.001
	%	13.3%	60.0%	20.0%	6.7%				
7. Do your parents keep asking you to seek treatment?	N	13	4	4	39	189	78.75	54.800	0.001
	%	21.7%	6.7%	6.7%	65.0%				
8. Do you feel life is not worth living with this disease?	N	31	20	5	4	102	42.50	33.467	0.001
	%	51.7%	33.3%	8.3%	6.7%				
9. Do you feel depressed?	N	12	7	6	35	184	76.67	36.933	0.001
	%	20.0%	11.7%	10.0%	58.3%				
10. Do you keep thinking about the disease?	N	15	3	7	35	182	75.83	40.533	0.001
	%	25.0%	5.0%	11.7%	58.3%				
11. Have you stopped or reducing going to parties/get togethers?	N	10	7	8	35	188	78.33	35.867	0.001
	%	16.7%	11.7%	13.3%	58.3%				
12. Do your friends/ relatives avoid you?	N	22	18	7	13	131	54.58	8.400	0.038
	%	36.7%	30.0%	11.7%	21.7%				
13. Do you think bringing your life to an end?	N	35	6	16	3	107	44.58	41.733	0.001
	%	58.3%	10.0%	26.7%	5.0%				
14. Do you observe any kind of dietary restrictions?	N	35	12	10	3	101	42.08	38.533	0.001
	%	58.3%	20.0%	16.7%	5.0%				
15. Does the amount of money you have spent on the treatment bother you?	N	8	19	10	23	168	70.00	10.267	0.016
	%	13.3%	31.7%	16.7%	38.3%				
16. Do you believe that this is the worst disease any one can have?	N	8	7	7	38	195	81.25	47.067	0.001
	%	13.3%	11.7%	11.7%	63.3%				
17. Do you get embarrassed when meeting people?	N	9	6	9	36	192	80.00	39.600	0.001
	%	15.0%	10.0%	15.0%	60.0%				
18. Do you worry about developing new lesions?	N	13	4	9	34	184	76.67	34.800	0.001
	%	21.7%	6.7%	15.0%	56.7%				
19. Do you have problems with your partner?	N	25	10	9	16	136	56.67	10.800	0.013
	%	41.7%	16.7%	15.0%	26.7%				
20. Do you anticipate problems in getting your children married?	N	13	4	4	39	189	78.75	54.800	0.001
	%	21.7%	6.7%	6.7%	65.0%				
21. Do your in-laws think this disease can spread to others in the family?	N	9	4	5	42	200	83.33	65.733	0.001
	%	15.0%	6.7%	8.3%	70.0%				
22. Do your in-laws stay worried about your white patches?	N	13	9	9	29	174	72.50	18.133	0.001
	%	21.7%	15.0%	15.0%	48.3%				
23. Does your relatives/in-laws have a problem in accepting your disease?	N	3	18	6	33	189	78.75	37.200	0.001
	%	5.0%	30.0%	10.0%	55.0%				
24. Are you facing a problem in getting married?	N	17	8	11	24	162	67.50	10.000	0.019
	%	28.3%	13.3%	18.3%	40.0%				
25. Do your colleagues treat you differently because of the disease?	N	36	15	4	5	98	40.83	44.133	0.001
	%	60.0%	25.0%	6.7%	8.3%				
26. Do your classmates treat you differently because of the disease?	N	21	6	6	27	159	66.25	22.800	0.001
	%	35.0%	10.0%	10.0%	45.0%				
27. Do you feel helpless?	N	9	10	4	37	189	78.75	44.400	0.001
	%								

Table 3: the relation between vitiligo impact and patients' bio-sociodemographic data

		N			T or F	T-test or ANOVA		
			Mean	±		SD	Test value	P-value
Age	Less than 25 years of age	31	81.258	±	11.849	T	4.733	<0.001*
	More than 25 years of age	29	62.552	±	18.287			
Sex	Male	41	65.976	±	17.774	T	-4.608	<0.001*
	Female	19	85.684	±	7.952			
Duration of disease	Less than 5 years	23	84.913	±	7.397	T	5.218	<0.001*
	More than 5 years	37	64.324	±	17.952			
Marital status	Single	26	85.077	±	7.025	F	46.412	<0.001*
	Married	17	49.294	±	16.046			
	Widow	10	74.900	±	1.969			
	Divorced	7	76.286	±	1.254			
Presence of vitiligo in the face	Yes	31	83.871	±	6.984	T	7.071	<0.001*
	No	29	59.759	±	17.570			
Family history of vitiligo	Yes	39	72.641	±	16.786	T	0.249	0.804
	No	21	71.429	±	20.114			
Level of education	illiterate	23	69.565	±	18.868	F	0.304	0.822
	Primary	20	74.800	±	16.923			
	Secondary	10	72.500	±	18.626			
	University	7	73.143	±	18.801			
Percentage of area involved	25% of total body surface area.	11	38.455	±	6.743	F	163.804	<0.001*
	26%-75% of total body surface area.	22	75.682	±	6.876			
	More than 75% of total body surface area.	27	83.148	±	7.183			

Figure 1: frequency distribution of the total vitiligo impact scale



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, the perception of deviation from normal appearance of the skin may generate a negative response from onlookers. Vitiligo is an acquired, multi-factorial and usually progressive disorder of melanin production. The psychological impact of vitiligo contributes to the severity of disease and may influence treatment outcome. The vitiligo impact scale was used to measure this impact and appears to be the second instrument developed exclusively for vitiligo^[11].

In relation to age, most of the present vitiligo patients were less than 25 years of age. This result agrees with that of other researches that revealed that this is the peak age of the persons with vitiligo, 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^[12]. In another series, 70% of the study population was below 30 years of age^[13]. Vitiligo, therefore, presents in the productive years when the negative psychosocial impact will have a vast effect on the economic output of the individual. There was no statistically significant difference between the ages of presentation of males and females ($p = 0.476$). **Salzes**^[14], however, noted earlier presentations in females and this is opposite to our finding.

Related to sex, the result of the study was in line with that of **Hedayat** who stated that vitiligo equally affects males and females as well as all different races. Vitiligo has various onset-age, distribution pattern and progression course. Vitiligo is the most prevalent cutaneous pigmentary disorder^[6]. Vitiligo patients with more than 5 years duration may be related to the chronicity of the disease regarding age, duration of disease, and presence of vitiligo in face. The results of the study are in agreement with those of **Olasode**^[15] while in relation to family history, there was contradiction between both.

The study showed that most studied patients have moderate to severe impact on psychological status. This result was congruent with **Chandler**^[2] and **Gawkrodger**^[16] who performed a similar study and revealed that the psychosocial impact of vitiligo is comparable to that of other common skin diseases such as psoriasis and eczema. Within the clinical guidelines, the main impact of vitiligo is the psychological effect of the disease. Moreover, within a UK survey, the majority of patients reported that vitiligo moderately or severely affected their QOL. Patients often reported feeling distressed and embarrassed about their appearance, which can lead

to low self-esteem, fear of rejection and social withdrawal. The key factors in this process are how people living with vitiligo interpret it, how they interpret themselves and how they interpret and respond to the experience of being in a social situation. In particular, patients have difficulties with social anxiety and high level of appearance-related concern^[17].

In addition, vitiligo is associated with high psychiatric comorbidity. Studies conducted in India have shown that 1 in 4 patients with vitiligo have psychiatric morbidity^[18]. Major depression, anxiety, and adjustment disorder are among the most common conditions experienced by patients. Suicidal ideation has been reported. Patients were unhappy with the way they now looked and seriously undermined the way they felt about themselves. The disease was a cause for worry, depression, and low self-esteem. Unmarried anticipate difficulty in getting married, and the disease was not revealed to the partner at the time of marriage due to embarrassment or the fear of rejection. One patient had been rejected by her in-laws and told to get divorced if not cured^[19]. The severity of the psychosocial impact can be seen in some patients who constantly thought about their disease. This study showed that there was a significant correlation between vitiligo impact scale and age, sex, duration of disease, marital status, presence of vitiligo in face and area involved. According to **Hedayat**^[6], there were not any association between VASI of exposed areas (face, hand, foot) and quality of life. Results were compatible with those of **Linthorst et al.**^[20].

Thus, counseling for 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 centers. 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 are essential and psychotherapist should participate in the management of the psychosocial problems of these persons. Additional work for more effective therapeutic modalities is advocated. Local herbal preparations and alternative therapy need to be looked into.

CONCLUSIONS

Vitiligo is a major psychological impact on patients. This psychological impact is significantly correlated with patient's age, sex, duration of disease, marital

status, the presence of vitiligo in the face, and percentage of area involved. However, there is no significant correlation between a family history of vitiligo, level of education and psychological impact of vitiligo.

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Disclosures

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REFERENCES

1. **Nguyen C, Beroukhim K, Danesh M et al. (2016):**The psychosocial impact of acne, vitiligo, and psoriasis: A review, *Clinical, Cosmetic and Investigational Dermatology*, 9: 383–392.
2. **Chandler D, Shah R, Shah R and Bewley A (2014):** The Psychosocial Complications of Vitiligo. *J. Pigment. Disord.*, 1(4):11-14.
3. **Ezzedine K, Eleftheriadou V, Whitton M and Van Geel N (2015):**Vitiligo. *Lancet*, 386(9988):74–84.
4. **Firooz A, Bouzari N, Fallah N et al.(2004):** What patients with vitiligo believe about their condition,” *Int. J. Dermatol.*, 43(11): 811–814.
5. **FDA(2006):**Guidance for industry: patient-reported outcome measures: use in medical product development to support labeling claims: draft guidance.*Health Qual. Life Outcomes*, 4:79.
6. **Hedayat K, Karbakhsh M, Ghiasi M et al.(2016):**Quality of life in patients with vitiligo: a cross-sectional study based on Vitiligo Quality of Life index (VitiQoL).*Health Qual. Life Outcomes*, 14(1): 86.
7. **Chren M and Weinstock M(2004):**Conceptual issues in measuring the burden of skin diseases.*Journal of Investigative Dermatology Symposium Proceedings*, 9(2):97–100.
8. **WHO (2014):** About the Global Burden of Disease (GBD) project, www.health.zone/Gbd Disease
9. **Ramam M, Pahwa P, Mehta M et al. (2013):**The psychosocial impact of vitiligo in Indian patients, *Indian J. Dermatology, Venereol. Leprol.*, 79(5): 679.
10. **Kostopoulou P, Jouary T, Quintard B (2009):**Objective vs. subjective factors in the psychological impact of vitiligo: The experience from a French referral centre.*Br. J. Dermatol.*, 161(1): 128–133.
11. **Meyer N, Paul C, Feneron D et al.(2010):***Psoriasis: An epidemiological evaluation of disease burden in 590 patients. J. Eur. Acad. Dermatology Venereol.*, 24(9): 1075–1082.
12. **European Medicines Agency(2005):**Reflection paper on the regulatory guidance for the use of health-related quality of life (HRQL) measures in the evaluation of Medicinal products. en.wikipedia.org/wiki/European_Medicines_Agency
13. **Ramam M, Mehta M, Sreenivas V et al.(2013):** Vitiligo impact scale: An instrument to assess the psychosocial burden of vitiligo. *Indian J. Dermatology, Venereol. Leprol.*, 79(2): 205.
14. **Salzes C, Abadie S, Seneschal J(2016):**The Vitiligo Impact Patient scale (VIPs): Development and validation of a vitiligo burden assessment tool.*J. Invest. Dermatol.*, 136(1): 52–58.
15. **Olasode O and George A(2008):**Psychosocial problems in patients with vitiligo in Nigeria. *Sudan. J. Dermatology*, 5(2): 51–58.
16. **Gawkrodger D, Ormerod A, Shaw L(2010):**Vitiligo: concise evidence based guidelines on diagnosis and management. *Postgrad. Med. J.*, 86 (1018): 466–71.
17. **Ongenaes K, Van Geel N, De Schepper S and Naeyaert J(2005):**Effect of vitiligo on self-reported health-related quality of life,” *Br. J. Dermatol.*, 152(6): 1165–1172.
18. **Talsania N, Lamb B and Bewley T(2010):**Vitiligo is more than skin deep: A survey of members of the Vitiligo Society. *Clin. Exp. Dermatol.*, 35(7): 736–739.
19. **Shah R, Hunt J, Webb L and Thompson A(2014):**Starting to develop self-help for social anxiety associated with vitiligo: using clinical significance to measure the potential effectiveness of enhanced psychological self-help. *Br. J. Dermatol.*, 171(2): 332–337.
20. **Linthorst Homan M, Spuls P, de Korte J(2009):** The burden of vitiligo: Patient characteristics associated with quality of life.*J. Am. Acad. Dermatol.*, 61(3):411–420.