

# Social participation in vitiligo patients and its association with quality of life

Mojgan Karbakhsh, MD <sup>1</sup>

Kosar Hedayat, MD <sup>2</sup>

Azadeh Goodarzi, MD <sup>3</sup>

Maryam Ghiasi, MD <sup>2</sup>

Narges Ghandi, MD <sup>2\*</sup>

1. Department of Community and Preventive Medicine, Tehran University of Medical Sciences, Tehran, Iran

2. Department of Dermatology, Razi Hospital, Tehran University of Medical Sciences, Tehran, Iran

3. Department of Dermatology, Rasool Akram Medical Complex, Iran University of Medical Science, Tehran, Iran

\*Corresponding author:

Narges Ghandi, MD

Department of Dermatology, Razi Hospital, Vahdate-e-Eslami St, Tehran, Iran

Postal code: 141556559

Email: [nghandi@tums.ac.ir](mailto:nghandi@tums.ac.ir)

Received: 17 February 2019

Accepted: 20 January 2020

**Background:** Vitiligo is a stigmatizing, chronic, and usually progressive skin disorder that affects patients' quality of life and can interfere with their social participation. There are no studies in developing countries focusing on this aspect. Hence, we assessed social participation in patients with vitiligo and its associations with Vitiligo Quality of Life (VitiQoL), Vitiligo Area Score Index (VASI), and demographic and clinical characteristics.

**Methods:** This cross-sectional study was conducted between 2013-2014 on 170 patients, in Razi Hospital, Tehran, Iran. In the pilot phase, the Persian version of the Participation Scale (P-scale) and VitiQoL questionnaire were validated with the backward-forward translation method.

**Results:** Among 173 vitiligo patients, the mean participation score was 15.12 (SD = 13.88, median = 11). Overall, 91 patients (52.6%) had no significant restriction, 38 (22%) suffered from mild, 23 (13.3%) moderate, 20 (11.6%) severe, and 1 (0.6%) suffered from extreme restriction in participation. The association between VitiQoL and P-scale was highly significant ( $r = 0.58$ ;  $P < 0.001$ ). This association was also observed with the three subscales of VitiQoL, namely participation limitation ( $r = 0.59$ ,  $P < 0.001$ ), behavior ( $r = 0.43$ ,  $P < 0.001$ ), and stigma ( $r = 0.23$ ,  $P = 0.002$ ). We did not find a significant association between P-scale and demographic characteristics, overall VASI, and face, genitals, and exposed areas VASI.

**Conclusion:** Although the majority of our patients perceived no or mild limitation in their social participation, the P-scale score was highly correlated with their quality of life and its components.

**Keywords:** vitiligo, social participation, participation limitation, participation scale, quality of life

Iran J Dermatol 2021; 24: 6-10

DOI: [10.22034/ijd.2021.128944](https://doi.org/10.22034/ijd.2021.128944)

## INTRODUCTION

Vitiligo is a common, immune-mediated, pigmentary disorder, which results in cutaneous amelanotic patches due to melanocyte destruction. The natural course of the disease is usually chronic and progressive, with variable age of onset, extension, distribution, and an unpredictable

response to treatment. Vitiligo usually presents in young adults who are generally the most productive community members and are in a very sensitive period of their lives regarding familial, social, and emotional relationships <sup>1-5</sup>.

Vitiligo is recognized to be a stigmatizing disorder that brings embarrassment and low self-confidence as it renders patients to be constantly occupied

with the dysmorphic self-body images<sup>6,7</sup>. As such, patients might withdraw from social interactions to avert a sense of rejection. The chronic nature, long treatment course, lack of uniform curative management, and unpredictable course of vitiligo are usually highly frustrating for patients, and the disease has major impacts on quality of life and can lead to social isolation<sup>8</sup>. Thus, vitiligo may interfere with patients' social participation and lead to social isolation<sup>9-21</sup>.

This paper aims to demonstrate the participation level of Iranian patients with vitiligo and its relationship with Vitiligo Quality of Life (VitiQoL).

## PARTICIPANTS AND METHODS

The Participation Scale (P-scale) evaluates the social participation level of stigmatized disorders like vitiligo and was developed based on the International Classification of Functioning, Disability and Health (ICF)<sup>7,22-24</sup>. It was developed in 2006 and used for the assessment of social participation in leprosy<sup>24</sup>; in 2011, it was validated for use in vitiligo patients<sup>6</sup>.

In the P-scale, the patients are asked to compare themselves with their peers to estimate the level of perceived limitation in various functions including learning and applying knowledge, general tasks, communication, mobility, self-care, domestic life, interpersonal interactions and relationships, major life areas and community, social and civic life. The scale is interviewer-administered and has six potential response options: the same as peers (0 points), not relevant (0), no problem (1), small problem (2), medium problem (3), and large problem (5). The total score on the scale is the sum of the scores of the individual items and can be categorized into "no significant restriction" (< 12), "mild restriction" (13-22), "moderate restriction" (23-32), "severe restriction" (33-52), and "extreme restriction" (53-90)<sup>25,26</sup>.

In this study, the original P-scale was translated from English to Persian by two bilingual physicians and then back-translated to English by two other bilingual physicians who had viewed the original questionnaire. After comparing the Persian version with the original one in an expert panel, the final questionnaire was developed after essential modifications.

This study had two parts: within the pilot phase,

25 vitiligo patients from the phototherapy clinic of Razi Hospital who consented to participate in the study filled in the VitiQoL and P-scale questionnaires. To examine the reliability of the study through test-retest, they were asked to re-fill these two questionnaires after 2-3 weeks. Within this interval, the patients received their routine treatment. In fact, due to the chronic nature of vitiligo, the treatment in this period was not supposed to improve their disease status, quality of life, or participation level. Details regarding the development of the Persian version of VitiQoL can be retrieved elsewhere<sup>27</sup>.

An estimate of the sample size was obtained based on the Lilly *et al.* paper<sup>4</sup> on the development and validation of VitiQoL. By adding 15% to this number (n = 139) to compensate for potential missings, the calculated sample size was 160. Finally, 173 patients were enrolled in the study. All vitiligo patients with the age of 16 years or more who did not have any history of a concurrent stigmatized disorder (like leprosy) or severe mental-psychological problems (like mental retardation or psychosis) were eligible to participate in the study. Through convenience sampling, 87 patients from the general dermatology clinic and 83 patients from the phototherapy clinic of Razi Hospital were recruited from April 2013 to September 2014.

After consent for inclusion in the study, patients' demographic data and clinical characteristics were assessed by the main investigator (a dermatologist). The dermatologist also examined vitiligo body involvement based on the Vitiligo Area and Score Index (VASI).

For analyzing data, SPSS ver. 22 was used. Data were summarized using mean, median, and standard deviation (SD) where appropriate; comparisons were made using the t-test and analysis of variance (ANOVA). The Pearson correlation coefficient was used for assessing the correlation between VitiQoL and P-scale scores.

## Ethical consideration

Consented patients were enrolled in the study after they received comprehensive information about the study objectives. Data were collected and analyzed confidentially. The Ethical Committee of Tehran University of Medical Sciences approved the study.

## RESULTS

A pilot study was conducted among 25 patients (13 female and 12 male) with a mean age of  $31.96 \pm 12.21$  years, confirming the favorable internal consistency of the Persian version of the P-scale (Cronbach's  $\alpha = 0.954$ ). In the main phase of the study, 173 patients (48.6% female and 51.4% male) were included with a mean age of  $31.96 \pm 11.91$  (median = 30) years. The mean social participation score of vitiligo patients was 15.12 (SD = 13.88; median = 11). In Table 1, the mean score for each item of the P-scale is demonstrated. Overall, 91 patients (52.6%) had no significant restriction, 38 (22%) suffered from mild, 23 (13.3%) moderate, 20 (11.6%) severe, and 1 (0.6%) from extreme restriction in participation. In Table 2, the relationship between participation limitation categories and patients' characteristics is elucidated. As we had just one patient with extreme limitation in participation, the last two categories (severe and extreme limitation in participation) were merged.

The association between VitiQoL and P-scale was highly significant ( $r = 0.58$ ;  $P < 0.001$ ). This association was observed across three subscales of VitiQoL: participation limitation ( $r = 0.59$ ,  $P < 0.001$ ), behavior ( $r = 0.43$ ,  $P < 0.001$ ), and stigma ( $r = 0.23$ ,  $P = 0.002$ ).

We did not find a significant association between the P-scale and VASI scores (correlation coefficient = 0.056;  $P = 0.46$ ). Even after excluding

three cases with nearly universal vitiligo, no association was still observed ( $r = 0.097$ ,  $P = 0.207$ ). Similarly, the VASI scores of the face, genitals, and exposed areas were not correlated with the P-scale score.

## DISCUSSION

Stigma is one of the most important factors that impact the quality of life and logically bring some degree of isolation that interferes with patients' social participation<sup>4</sup>. It is known that vitiligo is a stigmatizing disorder<sup>6,7,10,14,17,20</sup>, so evaluation of life quality, social participation, and associations between them would be worthwhile.

Overall, 91 patients (52.6%) had no significant restriction, 38 (22%) suffered from mild, 23 (13.3%) moderate, 20 (11.6%) severe, and 1 (0.6%) from extreme restriction in participation (mean score was 15.1). The study results were not completely similar to other previous studies on patients with vitiligo<sup>7</sup>. Pichaimuthu *et al.* compared participation limitation in psoriasis and vitiligo patients and showed they usually experience moderate to severe limitation in social relations, which makes them encounter many problems in ordinary activities (although less limitation was observed in the vitiligo group)<sup>7</sup>.

We did not find associations between P-scale score and age group, gender, education level, the extent of disease (VASI), skin phototype (Fitzpatrick), type of disease (generalized, segmental, or localized),

**Table 1.** Descriptive statistics of the items of the Participation Scale (P-scale) (range: 0–5)

Item No.	Participation domain	Mean	Standard Deviation	Median
1	Work opportunity	1.50	1.84	1
2	Work hard	0.83	1.50	0
3	Contribute economically	0.75	1.44	0
4	Visits out of the neighborhood	0.65	1.34	0
5	Attending rituals	0.87	1.42	0
6	Recreational/social activities	1.18	1.58	0
7	Religious/community participation	1.23	1.64	0
8	Having respect	0.67	1.19	0
9	Self-care	0.60	1.19	0
10	Long-term relationship	0.84	1.33	0
11	Visiting other people	0.59	1.10	0
12	Mobility inside and outside the house	0.92	1.47	0
13	Visiting public places	0.43	0.90	0
14	Doing household work	0.46	1.00	0
15	Having opinions in discussions	0.54	1.74	0
16	Helping other people	0.36	0.83	0
17	Comfortable meeting new people	1.48	1.71	1
18	Confident to try to learn new things	1.21	1.68	0

**Table 2.** Relationship between participation limitation and characteristic of vitiligo patients

Demographic and clinical characteristics	Categories n (%)	Participation limitation				P-value
		Non n (%)	Mild n (%)	Moderate n (%)	Severe or extreme n (%)	
Gender						
Female	84 (48.6)	41 (48.4)	15 (17.9)	16 (19.0)	12 (14.3)	0.094
Male	89 (51.4)	50 (56.2)	23 (25.8)	7 (7.9)	9 (10.1)	
Age group (years)						
16-19	28 (16.2)	12 (42.9)	10 (35.7)	2 (7.1)	4 (14.3)	0.086
20-29	49 (28.3)	22 (44.9)	7 (14.3)	12 (24.5)	8 (16.3)	
30-39	56 (32.4)	32 (57.1)	11 (19.6)	7 (12.5)	6 (10.7)	
≥ 40	25 (23.1)	25 (62.5)	10 (25)	2 (5)	3 (7.5)	
Education						
Illiterate	4 (2.3)	1 (25)	1 (25)	0 (0)	2 (50)	0.417
Grade 1-11	44 (25.4)	21 (47.7)	9 (20.5)	6 (13.6)	8 (18.2)	
High school diploma	76 (43.9)	43 (56.6)	16 (21.1)	11 (14.5)	6 (7.9)	
University education	49 (28.3)	26 (53.1)	12 (24.5)	6 (12.2)	5 (10.2)	
Skin phototype (Fitzpatrick)						
1,2	4 (2.3)	3 (75.0)	0 (0)	1 (25)	0 (0)	0.751
3,4	153 (88.4)	80 (52.3)	33 (21.6)	121 (13.7)	19 (12.4)	
5,6	16 (9.2)	8 (50)	5 (31.3)	1 (6.3)	2 (12.5)	
Type of disease						
Generalized	148 (85.5)	74 (50)	37 (25)	18 (12.2)	19 (12.8)	0.157
Localized	15 (8.7)	11 (73.3)	1 (6.7)	3 (20.0)	0 (0)	
Segmental	10 (5.8)	6 (60)	0 (0)	2 (20)	2 (20)	
Recruitment clinic						
General clinic	90 (52)	50 (55.6)	20 (22.2)	11 (12.2)	9 (10)	0.756
Phototherapy clinic	83 (48)	41 (49.4)	18 (21.7)	12 (14.5)	12 (14.5)	
Duration (years)						
< 5	63 (36.4)	37 (58.7)	11 (17.5)	11 (17.5)	4 (6.3)	0.526
5 - 10	33 (19.1)	19 (57.6)	6 (18.2)	2 (6.1)	6 (18.2)	
10 - 15	37 (21.4)	16 (43.2)	10 (27.0)	6 (16.2)	5 (13.5)	
15 - 20	13 (7.5)	8 (61.5)	2 (15.4)	1 (7.7)	2 (15.4)	
≥ 20	27 (15.6)	11 (40.7)	9 (33.3)	3 (11.1)	4 (14.8)	

Abbreviations: VitiQoL, Vitiligo Quality of Life; VASI, Vitiligo Area Score Index

recruitment clinic (phototherapy/general), or duration of the disease. Nevertheless, the P-scale score was highly correlated with the VitiQoL score and its subscales (participation limitation, behavior, and stigma).

Vitiligo is known as a stigmatized disorder with a confirmed impact on patients' quality of life (depending on disease/patient characteristics) and can logically result in social participation limitation<sup>8-21</sup>. Vitiligo by itself and with its related appendageal cosmetic concerns has a great impact on patients<sup>28</sup>. Hence, studying this disease as one of the most prevalent pigmentary disorders (especially among the young population)<sup>1-4</sup> and assessing the quality of life and social participation limitation of patients represent some of the most important issues in dermatology<sup>27-30</sup>. During vitiligo

management, it would be promising to pay more attention to boosting social participation, which may significantly reduce the social, financial, and emotional burden of this dermatological disorder.

In this study, patients were selected at a referral university hospital, which may not be representative of the overall community of vitiligo patients. However, our center (Razi Hospital) is the largest specialized dermatologic center in the country. Patients with some psychological problems (other than psychosis) were enrolled in the study as their exclusion might have led to a selection of a sub-sample that is potentially healthier than the normal general population.

For increasing the validity and reliability of the Persian version of the P-scale, future multi-center and community-based studies are recommended.

## Acknowledgment

This study was funded by the Tehran University of Medical Sciences, Tehran, Iran (*Registration code: 92-03-30-24653*).

The “My” company (an Iranian cosmetic company), as a voluntary initiative, provided an anti-solar cream to each participant to encourage them to use solar protection regularly. We would also like to show our gratitude to the Rasool Akram Medical Complex Clinical Research Development Center for its technical and editorial assistance.

**Conflict of interest:** None declared.

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