

Vitiligo Impact Scale (VIS)-22: A measure of the psycho-social burden of vitiligo

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Introduction

Vitiligo has a significant impact on the psyche, particularly in communities where the contrast with normal brown skin is disfiguring and the condition is socially stigmatized. This impact is usually assessed informally by talking to the patient and/or family members. But in some situations, both in the clinic and in clinical research, it is helpful to have a valid and reliable scale to measure the impact of the disease.

General dermatology scales such as dermatology life quality index (DLQI) and Skindex have been used for this purpose but because they were designed to be applied to a wide variety of skin disorders, these scales contain some questions that are not relevant to vitiligo (e.g., pain or pruritus) and do not cover aspects particularly relevant to vitiligo (e.g., difficulty in marriage). Till recently, vitiligo-specific quality-of-life scales were not available. Vitiligo Impact Scale (VIS) was developed in India in 2013. Around the same time, two other such scales VitiQol,¹ and Vitiligo Life Quality Index² were developed in the United States of America and Turkey respectively.

Development of VIS and refinement to VIS-22

VIS³ was developed with the aim of addressing the concerns of patients with vitiligo. The questions in the VIS were primarily generated from the results of an earlier qualitative study on the psychosocial impact of vitiligo on 50 patients using semi-structured interviews which identified their concerns.⁴ Other sources included relevant questions from other quality-of-life scales and suggestions from departmental faculty. The final VIS consisted of 27 questions. Internal consistency was demonstrated by Cronbach's alpha value of 0.83–0.85 for all items.³ The scale had 21 questions common to all patients, with five additional questions for married patients and one additional question for unmarried

patients. This imbalance in the denominator required the scale score to be calculated and expressed differently for these two groups of patients. To overcome this problem, item reduction analysis was used to reduce the number of questions for married patients to one and thus, equalize the number of questions for married and unmarried patients.

The modified scale, VIS-22 has 22 questions that cover different domains viz., attitude (questions 1, 4, 17, 19), anxiety (2, 11), social interactions (3, 12, 13), self-confidence (5, 18), depression (6, 9, 10, 14), treatment (7, 15, 16), family (8), marriage (20), occupation (21) and school or college (22). Each question is scored from 0 to 3 (0: not at all, 1: a little, 2: a lot, 3: very much). The total score ranges from 0 to 66 with higher scores indicating a higher effect on life [Figure 1a and b]. Patients find the scale easy to understand and complete.⁵

Validity of VIS-22

Validity refers to whether a scale measures what it intends to, and is one of the fundamental properties of a scale. Validity can be tested in different ways. Criterion validity refers to the correlation of the scale scores with another scale that is considered the gold standard. Convergent validity implies a positive correlation of the scale with other scales that measure the same variable. Known-groups validity assesses the scale's ability to discriminate between patients known to have differing characteristics.

The criterion, convergent and known-group validity of VIS-22 were demonstrated on a sample of 161 patients (age ≥ 15 years) with vitiligo. VIS-22 was found to have good criterion validity (strong correlation with patient-perceived severity on visual analogue scale, $r = 0.71$, $P < 0.001$)

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Vitiligo Impact Scale-22 (VIS-22)

This questionnaire is meant to measure the effect of vitiligo on your life. Please read every question carefully and answer them according to the best of your understanding.

0-Not at all

1- A little

2- A lot

3-Very much

		0	1	2	3
1	Do you think this disease is incurable				
2	Do you change your doctor				
3	Do suggestions and advice from others about the disease bother you				
4	Do other people feel that this disease spreads by touch				
5	Do you have problems in wearing your choice of clothes				
6	Do you feel helpless				
7	Do you face difficulties in adhering to the treatment				
8	Do your parents keep asking you to seek treatment				
9	Do you feel life is not worth living with this disease				
10	Do you feel depressed				
11	Do you keep thinking about this disease				
12	Have you stopped/reduced going to parties/get-togethers				
13	Do your friends/relatives avoid you				
14	Do you think about bringing your life to an end				
15	Do you observe any kind of dietary restriction				
16	Does the amount of money you have spent on the treatment bother you				
17	Do you believe that this is the worst disease anyone can have				
18	Do you get embarrassed when meeting people				
19	How worried will you be if you develop new lesions				

If you are married, please answer the following question

20	Do your in-laws worry about your white patches				
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If you are unmarried, please answer the following question

20	Are you facing problems in getting married				
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If you are working, please answer the following questions

21	Do your colleagues treat you differently because of the disease				
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If you are studying, please answer the following questions

22	Do your classmates treat you differently because of the disease				
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Figure 1a: English version of Vitiligo Impact Scale-22

Vitiligo Impact Scale-22 (VIS-22) (Hindi)

इस प्रश्नावली का उद्देश्य सफेद दाग वाली बीमारी का आपके जीवन पर होने वाले असर का आंकलन करना है। कृपया हर प्रश्न को ध्यान से पढ़ें और अपनी समझ के अनुसार उत्तर दें।

0=बिल्कुलनहीं

1=थोड़ा

2=बहुत

3=बहुतज़्यादा

		0	1	2	3
1	क्या आपको लगता है कि यह बीमारी ठीक नहीं हो सकती है?				
2	क्या आप डाक्टर बदलते हैं?				
3	क्या आप इस बीमारी से सम्बन्धित, लोगों की सलाह सुनते-सुनते परेशान हो जाते हैं?				
4	क्या दूसरों को लगता है कि यह बीमारी छूने से फैलती है?				
5	क्या आपको अपनी पसंद के कपड़े पहनने में परेशानी होती है?				
6	क्या आप लाचारी महसूस करते हैं ?				
7	क्या इस बीमारी का इलाज करवाने में आपको परेशानी होती है?				
8	क्या आपके माता-पिता आपको इलाज करवाने को कहते रहते हैं?				
9	क्या आपको लगता है कि इस बीमारी के साथ जीना बेकार है?				
10	क्या आप उदास रहते हैं?				
11	क्या आप इस बीमारी के बारे में सोचते रहते हैं?				
12	क्या आपने शादी-दावतों में जाना बन्द/कम कर दिया है?				
13	क्या आपके दोस्त-रिश्तेदार आप से मिलने में कतराते हैं?				
14	क्या आप ज़िन्दगी खत्म करने के बारे में सोचते हैं?				
15	क्या आप किसी तरह का खाने का परहेज रखते हैं?				
16	क्या इस बीमारी के इलाज में आपका काफ़ी पैसा खर्च हो गया है, जिससे आपको परेशानी होती है?				
17	क्या आप यह मानते हैं कि यह सबसे बुरी बीमारी है?				
18	क्या आपको लोगों से मिलने में शर्म आती है?				
19	आपको नए दाग बनने से कितनी चिन्ता होगी?				

अगर आप शादीशुदा हैं तो इन प्रश्नों का उत्तर दें

20	क्या आपके ससुराल वाले परेशान रहते हैं?				
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अगर आपकी शादी नहीं हुई है तो इस प्रश्न का उत्तर दें

20	क्या आपकी शादी होने में परेशानी आ रही है?				
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अगर आप नौकरी कर रहे हैं तो इन प्रश्नों का उत्तर दें

21	क्या इस बीमारी की वजह से आपके सह-कर्मचारियों के व्यवहार में कोई फ़र्क पड़ा है?				
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अगर आप पढाई कर रहे हैं तो इन प्रश्नों का उत्तर दें

22	क्या इस बीमारी की वजह से आपके सहपाठियों के व्यवहार में कोई फ़र्क पड़ा है?				
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Figure 1b: Hindi version of Vitiligo Impact Scale-22

and convergent validity (strong correlation with DLQI, $r = 0.71-0.78$, $P < 0.001$; skindex-16, $r = 0.72-0.79$, $P < 0.001$). Known-groups validity for VIS-22 scores was shown by higher scale scores for groups expected to have a higher level of distress related to vitiligo; women, patients with progressive disease and those with lower education.⁵

Test-retest reliability of VIS-22

If a patient's disease is unchanged between two visits, the scale score should also remain unchanged; this is referred to as test-retest reliability. A two-week interval is chosen between visits so that enough time has elapsed for the person to forget their previous responses but not so much time that the disease has changed significantly.

VIS-22 was administered to 69 patients at an interval of two weeks and the scores at baseline ($27.16 + 14.33$) and at two weeks ($27.26 + 15.62$) showed a high correlation ($r = 0.91$, $P = 0.049$).⁵ This indicates that the scale is reliable.

Responsiveness of VIS-22

Scale scores should change when the quality-of-life changes: they should go up if the patient is feeling worse, and go down when they feel better. If the patient feels a lot worse, the score should change more than if they feel only slightly worse, and similarly when they feel better.

This property, referred to as responsiveness, was demonstrated for VIS-22 in 72 patients who were tested at baseline and at the end of 12 weeks. The change in VIS-22 scores correlated moderately well ($r = 0.49$, $P < 0.001$) with the change in patient-perceived vitiligo distress. The VIS-22 scores were statistically significantly higher ($P < 0.001$) in patients whose distress had worsened as compared to those whose distress had reduced. The change in VIS-22 scores also mirrored the change in disease activity; VIS-22 scores were statistically significantly higher when vitiligo worsened, did not change significantly when clinical status remained unchanged and showed a graded decrease for every degree of clinical improvement.⁵ Similarly, a graded change in VIS-22 scores corresponding to improvement or worsening in the patients' quality of life was recorded in a subsequent study.⁶

Clinical meaningfulness of VIS-22 scores

Scale scores are numbers but dermatologists need to know how to interpret the numbers; what does a particular score say about the severity of impact? Interpretability or clinical meaningfulness refers to assigning a severity grade (for example, mild, moderate or severe) to the scale scores.

A study of a cohort of 391 patients showed that a VIS-22 score of 0–5 indicates no impact; 6–15, mild impact; 16–25, moderate impact; 26–40, large impact and 41–66, very large impact.⁷ The interpretability of VIS-22 scores was studied using an anchor-based approach where a global question

(GQ) concerning the effect of vitiligo on patients' lives ("How much does vitiligo affect your life?") on a five-point Likert scale: 0, no effect; 1, mild effect; 2, moderate effect; 3, large effect and 4, very large effect was used as the anchor. The VIS-22 scores showed a good correlation with the GQ score ($r = 0.76$, $P < 0.001$).

Overall, the VIS-22 bands agreed with GQ bands in 197 (51.6%) patients. This was statistically significantly better than the agreement of DLQI bands with GQ in 138 (36.1%) patients. On comparing VIS-22 with DLQI, the latter misclassified patients more frequently (VIS-22, 7.9% vs DLQI, 15.4%). In addition, DLQI placed patients in a lower distress category more frequently than VIS-22 (50.8% vs 20.9%). These findings suggest that VIS-22 may be better than DLQI in assessing vitiligo-related burden and categorizing its severity.⁷

Minimal important change of VIS-22 scores

If a patient's scale score is 20 on one occasion and 24 at a follow-up visit three months later, does this represent worsening? If the scores are 36 and 30 respectively, does this mean the patient is feeling better? The minimal important change of a scale refers to the smallest difference in its scores that are considered clinically significant by the patient or clinician.

The minimal important change of VIS-22 scores was estimated to be five points for both improvement as well as worsening. The minimal important change of VIS-22 scores was estimated in a study on 309 patients using an anchor- and distribution-based approach.⁶ For this purpose, a GQ (see above) and a global rating of change question concerning the change in quality-of-life on a five-point Likert scale (–2, a lot worse; –1, worse; 0, no change; +1, better; +2, a lot better) were used as anchors, while standard error of measurement and one-half of standard deviation was considered as distribution-based estimates. The various estimates for the minimal important change in VIS-22 ranged from 4.1 to 7.05 for both improvements as well as worsening. Practically, a single estimate of five points may be considered as the minimally important change of VIS-22 scores in either direction. In simple terms, it means that a change of VIS-22 scores by five points or more should imply a clinically significant change in the quality of life of the patient.

Limitations

The scale was developed in a culture where vitiligo places a heavy psycho-social burden on patients; its validity in other cultures needs to be studied. A Chinese study found that VIS-22 was better than DLQI in covering aspects of attitude, anxiety and family worries but lacked questions about physical symptoms and sexual activity. They also mentioned that some questions were not suitable for Chinese patients, though they did not mention which ones were unsuitable.

Language versions

VIS-22 was developed in English and Hindi. Studies using Kannada,⁸ Chinese⁹ and Urdu¹⁰ versions have been published. An unpublished Arabic translation prepared by Egyptian researchers is also available (personal communication).

Permission for use

Permission to use VIS-22 is required but academic, non-commercial use is permitted free of charge. Permission can be obtained by emailing a request to the authors of the scale.

Conclusion

VIS-22 is a valid, reliable and responsive vitiligo-specific quality-of-life scale that was developed to address issues important to patients.¹¹ Scale scores range from 0 to 66 and a score of 26 or higher indicates large or very large impact. A change in score of 5 or more is clinically significant. It is a tool that has been used for vitiligo research^{8-10,12-14} and can also be used in the clinic.

Declaration of patient consent

Patient's consent not required as there are no patients in this study.

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Nil.

Conflicts of interest

The authors are members of the team that developed VIS-22.

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