

## Measuring the severity of vitiligo

*M. Ramam, S. Gaurang Krishna*

A defined and validated index of severity is important to classify patients, decide on therapeutic options and to compare treatment outcomes; however, such assessment methods are lacking for vitiligo at present.

### AREA OF INVOLVEMENT

Published reports largely utilise body surface area involvement as a measure of severity and to assess recovery. The Wallace rule of nines, and its corollary of treating the area of hand as approximately 1% is most commonly used in clinical studies and in practice.<sup>[1,2]</sup> The Lund-Browder Chart (a similar technique devised for burns but composed of smaller segments) has been suggested as an alternative.<sup>[1]</sup> Point counting, digital planimetry, and digital photography with computerized planimetry and computer aided design software are some of the other methods that have been used to measure area.<sup>[3-7]</sup> Inter-observer agreement using these methods was acceptable in some studies,<sup>[1]</sup> while other workers found significant variation when lesional area was calculated by visual assessment.<sup>[3]</sup> Using these techniques, repigmentation following an intervention is reported as a percentage of the original area of depigmentation. Clearly, a statement of the percent repigmentation alone is unhelpful and hence

the convention of considering repigmentation to be excellent when it exceeds a certain cut-off (75%-90%). However, considering the significance of complete repigmentation to patients (and their doctors), there is a strong case for specifying the number of patients in each study who achieved complete repigmentation and not lumping them with others who had substantial but incomplete repigmentation.

The principle underlying body surface area measurements is that the greater the involvement of the skin, the more severe the disease. Conversely, a reduction in the affected area is equated with improvement. Is this always true in vitiligo? A facile example of a situation where this is not so is universal vitiligo: here, the progression of depigmentation over the entire skin is perceived as a desirable outcome preferable to patchy (though less extensive) vitiligo. In fact, patches of pigmented skin that develop in such patients are sought to be removed (thus increasing the area of vitiligo). Another example is the increase in pigmented areas within a patch which may amount to a quantitative decrease in the extent of depigmentation but lead to mottling and a poor cosmetic appearance; an outcome that is not captured by a measure that reports improvement merely as percentage repigmentation. The severity of a patch of vitiligo of a particular dimension is significantly greater if it is located on the face, exposed skin or sexually important sites such as the breasts or genitals and the size is inadequate as a sole measure in these settings.

Department of Dermatology and Venereology, All India Institute of Medical Sciences, New Delhi, India

#### Address for correspondence:

Dr. M. Ramam, Department of Dermatology and Venereology, All India Institute of Medical Sciences, New Delhi – 110 029, India. E-mail: mramam@hotmail.com

### DISFIGUREMENT

A more direct measure of the disfigurement caused by vitiligo and the improvement produced by treatment would be the use of a disfigurement index. The burden of vitiligo is both external and internal. The alteration in appearance as perceived by others is an important component of the disease: this can be measured by a disfigurement index. The impact that the disease has on an individual and his psyche is another important

Access this article online	
Quick Response Code:	Website: www.ijdv.com
	DOI: 10.4103/0378-6323.90939

**How to cite this article:** Ramam M, Krishna SG. Measuring the severity of vitiligo. Indian J Dermatol Venereol Leprol 2012;78:5-7.

**Received:** August, 2011. **Accepted:** August, 2011. **Source of Support:** Nil. **Conflict of Interest:** None declared.

component and this is measured by scales and questionnaires that evaluate the quality of life related to the disease.

Disfigurement indices have been described in some conditions including Grave's ophthalmopathy,<sup>[8]</sup> port wine stains<sup>[9]</sup> and following surgery for head and neck cancer.<sup>[10]</sup> Essentially, the process consists of submitting photographs of patients to a panel of observers and asking them to score the disfigurement caused by the condition on a scale such as the visual analogue scale. The observers used in the study have been medical professionals, patients and lay people. Some differences were noted in the scores provided by different groups of raters; however, in general, there was agreement within the groups.

A similar index could be developed and applied to the assessment of vitiligo both in clinical practice and in therapeutic trials.

### **PROGRESSION OF DISEASE/DISEASE STABILITY**

Another important criterion that determines the severity of vitiligo is the potential for spread. This is reflected in the statement by many patients that they would not be greatly concerned about the disease if they could be assured that it would not spread further. Currently, disease progression can be most robustly predicted in segmental vitiligo where depigmentation is likely to be confined to one anatomical segment in the vast majority. The reliable identification of segmental vitiligo is an important component of the assessment of disease severity.

Non-segmental vitiligo behaves very variably in different patients and there are presently no criteria to identify the likely course in a patient. Some workers have suggested the use of certain clinical findings such as punctate depigmentation, differing tones of hypopigmentation around the lesions, sharpness of the margin and repigmentation as markers of disease activity,<sup>[11]</sup> while others have advocated the use of the Wood's lamp.<sup>[1]</sup> A formal validation of these criteria has not been undertaken.

Arbitrary definitions of disease progression have been used by different workers,<sup>[12]</sup> and have also been used to construct scales of disease activity.<sup>[13]</sup> The principle of these measures is that the longer the time elapsed since the development of new lesions or the extension

of old lesions, the more stable the disease is likely to be. In effect, the course of the disease in the past is used to predict its likely course in the future. The recommendation to undertake vitiligo surgery after 1 year of inactivity is based on a similar assumption.<sup>[14]</sup> Unpublished data from our department suggests that this assumption may not be valid and that disease activity may recur even after periods of quiescence of 1 year or more. There is an urgent need to collect follow up data on patients who have achieved stability to see how long the disease can be expected to remain quiescent and what factors influence this outcome.

### **POTENTIAL FOR REPIGMENTATION**

The likelihood of having a satisfactory response to treatment is also a measure of disease severity. Once again, a therapeutic response can be predicted most confidently in segmental vitiligo, where a poor response to medical therapy and a good response to surgical therapy is the rule. It is also well recognized that areas such as the mucosa, hands, feet and bony prominences and patches showing leukotrichia respond poorly to treatment. Finally, the extent of depigmentation appears to be important because cosmetically satisfactory repigmentation is unlikely to occur in patients having involvement of extensive skin areas.

### **PSYCHO-SOCIAL IMPACT**

Vitiligo has a major impact on the quality of life (QOL) of patients,<sup>[15]</sup> and any assessment of disease severity needs to address this important component of the clinical picture. While the disfigurement index measures how a person's vitiligo is perceived by others, assessment of the psycho-social impact of the disease measures how the vitiligo is perceived by the patient. Several workers have pointed out that the psycho-social burden is not directly correlated with the clinical severity of vitiligo<sup>[16]</sup> and this indicates the need to evaluate the psycho-social impact of vitiligo independently. Generic health-related QOL and dermatology specific instruments have been used but the availability of a vitiligo-specific questionnaire will be helpful in accurately and comprehensively mapping the psycho-social burden of the disease.

### **CONCLUSION**

In assessing the severity of vitiligo, the emphasis has

been on measuring the extent of skin depigmentation. While this is important, other factors including the disfigurement caused by the disease, likelihood of spread, potential for repigmentation and the psychosocial impact also need to be measured to obtain a comprehensive picture of the disease in order to direct interventions to areas requiring attention and to document the effect of such interventions. A composite index is likely to be a cumbersome compromise that does not adequately measure any attribute; it may be best to have different scales for each factor. However, this would make it difficult to apply in clinical practice and a briefer version of the scales may need to be developed for this purpose. Clearly, there is much to be done.

## ACKNOWLEDGEMENTS

Drs. J A Sundharam, B K Khaitan, V Ramesh and C R Srinivas read the manuscript and made helpful suggestions.

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