The burden of vitiligo: Patient characteristics associated with quality of life

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Background: Vitiligo is commonly regarded as a harmless cosmetic skin problem in Western societies, and the importance of treating patients with vitiligo is often underestimated.

Objective: We sought to determine the clinical and sociodemographic variables that adversely affect the quality of life in adult patients with generalized vitiligo so that these variables can be considered in the treatment and care.

Methods: A total of 245 adult patients with generalized vitiligo completed two quality-of-life questionnaires (the Medical Outcomes Study 36-Item Short-form General Health Survey and the Skindex-29). Physicians assessed sociodemographic and clinical characteristics of these patients.

Results: Dark skin type, vitiligo located on the chest, and treatment in the past appeared to have an adverse impact on the psychosocial domains of quality of life. Moreover, itch was reported by 20% of the patients in this study.

Limitations: Psychiatric comorbidity was not evaluated in the analyses.

Conclusion: Generalized vitiligo is a serious skin disorder with an adverse impact on the emotional state, comparable with that of other major skin diseases. (J Am Acad Dermatol 2009;61:411-20.)

Key words: quality of life; SF-36; Skindex-29; vitiligo.

Millions of men and women worldwide have vitiligo. The most common clinical variety is the so-called nonsegmental or generalized vitiligo,[1] in which scattered milky-white skin patches may appear all over the body because of loss of functional melanocytes. Many patients with vitiligo experience psychosocial distress and social stigmatization.[2-4] Because skin color plays a major role in an individual's perception of health, wealth, worth, and desirability, pigmentary disfigurements may influence social interactions.[5] Vitiligo may even lead to social exclusion in certain societies. Therefore, vitiligo is considered to be one of the major medical problems in India.[6,7] However, in Western-European countries, although associated with other autoimmune diseases,[8] vitiligo is often considered as a harmless, cosmetic skin disorder, whereby the importance of treating patients with vitiligo is often underestimated.[4,9,10] Nevertheless, it is important to recognize and deal with the psychosocial impact of this disease.[7] We evaluated the burden of vitiligo taking a broad range of factors into account to compile a profile of patients with vitiligo who suffer most and require special medical care.

Abbreviations used:

HRQL:	health-related quality of life
MCS:	Mental Component Summary
NIPD:	Netherlands Institute of Pigment Disorders
PCS:	Physical Component Summary
SF-36:	Medical Outcomes Study 36-Item Short-form General Health Survey

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One way of evaluating the burden of a disease is by measuring the health-related quality of life (HRQL), ie, using standardized questionnaires to measure the impact of a disease on the physical, psychologic, and social functioning, and the well-being of the patient.[11,12] A number of studies has examined HRQL in patients with vitiligo.[3,7,13-20] These studies focused mainly on specific questionnaires in dermatology and reported that, in general, vitiligo had an adverse impact on HRQL, particularly on psychosocial functioning. There are no studies in vitiligo in which a combination of a generic and a dermatology-specific HRQL questionnaire was used. A wide range of domains and aspects of quality of life can be assessed by using this combination. Moreover, both types of instruments may measure different but complementary domains and aspects of patient health,[21,22] and the use of a generic HRQL questionnaire, such as the Medical Outcomes Study 36-Item Short-form General Health Survey (SF-36), allows comparisons with other medical conditions, not just skin diseases.

CAPSULE SUMMARY

- In our study, patients with vitiligo reported emotional problems on the Skindex-29 comparable with those of patients with psoriasis, eczema, chronic hand dermatitis, and acne.
- Vitiligo particularly had an impact on HRQL of patients with dark skin, patients with vitiligo on the chest, and patients who had treatment in the past. Vitiligo on visible locations (eg, hands and face) did not interfere with HRQL.
- Vitiligo was associated with itch in 20% of the patients.

The first aim of this study was to determine the generic and the dermatology-specific HRQL in sociodemographically and clinically distinct subgroups of patients with generalized vitiligo. The second aim was to investigate associations between HRQL and sociodemographic and patient clinical characteristics to include these characteristics in the treatment and care of patients with generalized vitiligo.

METHODS

Patients

All consecutive adult patients (age ≥ 18 years) with generalized vitiligo, referred to the Netherlands Institute of Pigment Disorders (NIPD) from January to December 2006, were invited to participate in the study. Patients who did not speak or read Dutch, who were mentally and/or physically unable to complete the study questionnaires, or who had an additional skin disease were excluded. Patients provided informed written consent.

Medical ethics approval was sought, but was considered not to be required by the medical ethics committee (in the Netherlands approval is only required for self-report questionnaires containing intrusive items).

Measures

Outcome measures. *Generic quality of life: The SF-36.* This widely used questionnaire consisted of 36 items forming 8 domains or scales: physical functioning; social functioning; role physical (limitations in usual role activities because of physical problems); role emotional (limitations in usual role activities because of emotional problems); bodily pain; mental health; vitality; and general health perceptions. We used the validated Dutch translation of the SF-36.[23] The questions referred to the previous 4 weeks. A score from 0 to 100 was calculated for each scale, with higher scores indicating better quality of life. Two summary scores were calculated, the Physical Component Summary (PCS) and the Mental Component Summary (MCS), by adding weighted combinations of the 8 scales. The summary scores were converted to standardized T scores that had a mean of 50 and SD of 10. A summary score of 50 (SD 10) reflected an average quality of life of the general population.[23,24]

Dermatology-specific quality of life: Skindex-29. This questionnaire consisted of 29 items forming 3 scales: symptoms (eg, itch, pain, and irritation); emotions (eg, worry, shame, embarrassment, frustration, and depression); and functioning (eg, sleep, social life, social isolation, sexuality, work, and hobbies). The questions referred to the previous week; scores were given on a 5-point scale, from "never" to "all the time." Scale scores and a sum score were calculated on a 100-point scale, with lower scores indicating a better quality of life.[25]

Independent measures. The sociodemographic data included age and sex. The clinical data included duration of disease, vitiligo disease activity,[26] treatment history, treatment effect, current treatment, symptoms (eg, sunburn and/or itch on the depigmented areas as distinct symptoms), comorbidity, smoking, skin type,[27] affected body sites, and extent of the disease (in percent). These data were collected using a study-specific questionnaire and dermatologic examination was performed by the