



Psychosomatic aspects of vitiligo

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Abstract Vitiligo is a chronic common skin disease. The asymptomatic hypopigmented cutaneous lesions are considered by many health care professionals as a cosmetic problem only; however, vitiligo can have a major psychosocial impact on patients' lives. We review some of the factors responsible for this impact, such as the general public's wrong perception of the disease, feelings and emotional responses from patients, how stressful events can act as triggers of the disease, stigmatization experiences suffered by the patients, the prevalence of psychiatric morbidity, the effects on relationships and sex life, how quality of life in adults and children is impaired, and how treatment can improve it.

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Introduction

Vitiligo is a chronic acquired disease of pigmentation that affects about 1% of the world's population. It is characterized by hypopigmented and asymptomatic macules with well demarcated margins caused by the destruction of melanocytes in the skin.¹ Vitiligo affects both genders equally, although women complain earlier and more frequently about it. It can develop at any age but usually before the age of 30.²

Although the etiology of vitiligo remains unclear and several theories have been developed, the autoimmune hypothesis remains the most acceptable.³ Because vitiligo does not cause physical disability, it is often considered a cosmetic problem only; however, the changes caused by the disease may affect the emotional and psychologic well-being of patients and have a significant impact on their lives. People with vitiligo often have a negative self-image and low self-esteem. In addition, they may suffer stigmatization and be ashamed of their body, which impairs

social life.⁴ We review the psychosomatic aspects of the disease, which must be considered when treating and monitoring patients with vitiligo. We emphasize the importance of adequate instruments that have been developed so far to have a detailed picture of individual impact of the disease.

General public's perception and the role of cultural factors

Misconceptions and negative attitudes about vitiligo among the general public are prevalent. Thirty-three percent of individuals who answered a questionnaire believed that vitiligo is contagious or did not know that it is not. The cause of vitiligo was thought to be infectious by 20.4%, inherited by 40.5%, autoimmune by 41.2%, and due to a lack of hygiene by 22.5%.⁵

A large survey performed by a UK patient support group indicated that most respondents obtained information about their vitiligo from nonmedical sources: 83% from the support group, 25% from the Internet, and only 12.5% from dermatologists.⁶

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Cultural factors, religious and spiritual beliefs, diet, style of clothing, sun exposure, and socioeconomic status can play a major role in the psychosocial impact of vitiligo. In patriarchal societies, with regard to inheritance and marriage, for example, female beauty is of great value in the arranged marriage market, so the burden on women is greater.⁷

Emotional response

A questionnaire was applied in a study of 100 patients concerning their perspective about vitiligo. The questionnaire had a single question with multiple answers: "What do you feel when you look at your spots or when you think of them?" The majority of patients with lesions in exposed areas expressed psychological complaints (88%), whereas only 27% of those with lesions in unexposed areas complained of some discomfort. In the group of patients studied, the most cited answers were fear (specifically that the spots will spread) (71%), shame (57%), insecurity (55%), sadness (55%), inhibition (53%), displeasure (50%), impatience (43%), irritability (36%), unhappiness (35%), negative image to others (35%), anger (26%), bitterness (25%), lack of self-confidence (25%), being disgusted with yourself (18%), and others (16%). No patient cited any positive feeling about the disease, although they were able to do so.⁸

Alexithymia is a multifaceted personality trait comprising difficulties identifying and describing feelings, a lack of imagination, and an externally oriented thinking style.⁹ A case-control study used the 20-item version of the Toronto Alexithymia Scale.^{10,11} It is divided in three subscale scores: the difficulty in identifying feelings; the difficulty in describing and communicating feelings; and the tendency to focus on the concrete details of external events rather than on feelings, fantasies, and other aspects of one's own inner experience ("externally oriented thinking"). Patients with vitiligo scored significantly higher than controls on the 20-item Toronto Alexithymia Scale, and they were significantly more likely to be classified as alexithymic or borderline alexithymic than controls. In relation to the Toronto Alexithymia Scale dimensions, cases scored higher than controls on the subscale measuring externally oriented thinking, and they also tended toward higher scores on the subscale measuring difficulty in identifying feelings.¹²

To evaluate the temperament of patients, a cross-sectional study with first-onset vitiligo and alopecia areata patients and healthy controls used the Temperament and Character Inventory.¹³ Among the temperament traits, the extravagance, disorderliness, and total novelty-seeking scores were lower and the worry and pessimism scores were higher in patients with vitiligo compared with patients with alopecia areata and healthy controls.¹⁴

Stressful events as triggers

Stressful life events can act as triggers for vitiligo. A recent large scale questionnaire-based study assessed 1541 adults

with vitiligo to evaluate the impact of psychologic stressors in this patient population. Among participants, 56.6% experienced at least one death or stressor within 2 years before vitiligo onset, including death of a loved one (16.6%) and stressful life events (51.0%), especially work/financial problems (10.8%), end of a long-term relationship (10.2%), and family problems (7.8%). The majority who experienced death reported one death (13.5%), and others reported multiple deaths (3.1%). For those who experienced stressful events, 33.6% reported experiencing one stressor and 17.4% reported multiple stressors. The number of deaths or stressors reported per participant within the 2 years before the onset of vitiligo was not associated with BSA or distribution of lesions.¹⁵

The results of this large sample study are consistent with prior smaller studies, which identified a high frequency of stressful events preceding vitiligo onset in children and adults.^{12,16–19}

Stigmatization experiences

More than 50% of vitiligo patients report they had been stared at, 16% had overheard rude remarks, and 13% of patients say they have encountered job discrimination due to their vitiligo.²⁰ In a study with more than 600 patients, 59% reported an incident in the past 3 weeks in which their vitiligo had made them feel bad.²¹

One study asked questions aimed at vitiligo-related information and applied the Adjustment to Chronic Skin Disorders Questionnaire²² to 96 patients. Minor (low-key) stigmatization (questions about their appearance by strangers) was a frequent experience reported by 90% of patients, and 24% stated that this had happened "very often." Patients with no other affected family member reported more often low-key stigmatization. Major (high-key) stigmatization, such as "picking on" or "nasty" comments, was not frequent, and 76% patients "never" experienced it. Patients with severe vitiligo on the arms and trunk more often experienced high-key stigmatization. The Adjustment to Chronic Skin Disorders Questionnaire focuses on coping with chronic skin diseases and found that 66.7% patients had avoided situations, including "swimming/bathing," "getting undressed in changing rooms," "shaking hands," and "sports," and two-thirds of the group had "quite often" or "very often" concealed their white spots in public.²³

A German study of 363 patients using the Experience with Skin Complaints,²⁴ Adjustment to Chronic Skin Disorders,²² and Sense of Coherence²⁵ questionnaires indicated that women's "retreat" (avoidance of public situations and special ways of clothing) and low "composure" (calmness and confidence in a satisfactory life in spite of the skin disease) regarding the stigmatization experience led to more perceived helplessness in coping with the disease. The results of the Coherence scale indicate a burden of disease regarding symptoms of anxiety, depression, or subjective stress.

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