Vitiligo - Quality of Life Issues in North Macedonia

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Abstract

Vitiligo causes loss of pigment on the affected areas of the skin and/or mucosae.

It is characterized by milky white, non-scaly macules with distinct margins. Vitiligo has more than a 3000-year history, it was often confused with leprosy and led to greater stigmatization of affected individuals. Vitiligo affects patient’s QoL in all of the four different aspects: physical, psychological, social, and occupational. Psychological aspect is the most influent factor that affects the QoL of vitiligo patients. It derives from various subjective symptoms such as depression, anxiety, anger, embarrassment, self-consciousness. We present for the first time the data on the quality of life in a group of patients in North Macedonia.

Keywords: Vitiligo, quality of life QoL, depression, anxiety, leprosy, stigmatization

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INTRODUCTION

Quality of Life (QL) is defined by the WHO (World Health Organization) as the perception of individuals about their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns (1).

Vitiligo is an acquired de-pigmentary disease characterized by white macules on the skin, mucous membranes, and hair due to the selective destruction of the number and the quality of melanocytes (2).

According to the definition of Vitiligo European Working Group, Vitiligo vulgaris is an acquired chronic pigmentation disorder characterized by white macules, often symmetrically distributed, which usually increase in size over time, corresponding to a significant loss of function of the epidermal melanocytes and some times of the hair follicles (3). Following the classic morphology of vitiligo, the lesions are discrete, uniformly milky-white macules of round, oval, or irregular shape ranging in size from millimetres to many centimetres, surrounded by normal or hyper pigmented skin. The disease is asymptomatic, but in some cases itching or a burning sensation may occur. Vitiligo appears in areas of friction that are usually hyperpigmented such as the face, dorsal surface of the hands, axilla, nipples, sacrum, inguinal and anogenital regions and the surface of the joints. Leukotrichia develops in 3.7-47.3% of vitiligo cases (4,5). Mucosal involvements have been reported between 7.4-74% in generalized vitiligo types (6).

Synonyms

Synonyms for vitiligo vulgaris are leukoderma, depigmentation, and acquired depigmentation (7).

Epidemiology

The prevalence of vitiligo is 0.5% to 1% in Europe and the United States, but ranges from 0.1% in China to 8.8% in some regions of India (7). Vitiligo affects both sexes and in 50% of cases the disease appears before the age of 20. The disease occurs with an estimated prevalence of 0.15–3.0% in Western Europe and Turkey, about 1% in the United States, 2.6–4% in Mexico, 0.1–8.8% in India, and 0, 1–0.6% in China (8).

Most studies have proven that vitiligo is present in both sexes equally, but there are also studies where women predominate. Such superiority in the female population can be explained by the desire to look good (the request to see the doctor and to treat the pathology is higher in this group) and the willingness to seek medical help to achieve this desire (9,10,11). Loss of pigmentation can begin at any age during life. The usual age of onset of vitiligo is between 10 and 30 years, and in half of the cases the disease begins before the age of 20, in 70-80% of the cases before the age of 30 (12,13).

A positive family history influences the onset of vitiligo and in those cases the disease appears earlier than in sporadic cases (14,15). The simplest classification divides vitiligo into segmental and non-segmental type, based on the clinical course and different distribution on the body. In 2011, the classification of vitiligo was revised at the consensus conference of the Global Vitiligo Conference (16). According to the consensus, the segmental type of vitiligo should to be classified separately from all other types of vitiligo. According to the extent and distribution of pigment loss, they differentiated the disease as localized, generalized and universal with several subtype (15).

Stigmatization

People with dark skin color are more stigmatized (17,18).

The chronic nature of the disease, long-term treatment, lack of equally effective therapy, and the unpredictability of the condition are usually very demoralizing for patients who have vitiligo (19).

Moreover, many health professionals still consider vitiligo as a harmless cosmetic skin problem, failing to include the psychological and sociological components that are so closely related to this disease and consequently underestimating the importance of treating these patients (20).

QUALITY OF LIFE

Several studies have analyzed the various factors that affect the quality of life of patients with vitiligo. Results in most studies show a moderate impact of vitiligo on quality of life. Several studies have reported differences between quality of life in patients with vitiligo and other groups. Factors most commonly associated with reduced QL in patients with vitiligo were noticed mostly in females. Compared to healthy controls, QL in patients with vitiligo was significantly reduced in 13 studies (19,20). Compared to other dermatological diseases, QL in patients with vitiligo were significantly low. It is noticed lower compared to melasma.

The highest value of Dermatology Index of Quality of Life (QOL) was observed in the group of patients aged 20-29 years. There is a correlation between QOL and marital status, skin type and disease progression. In addition, vitiligo negatively affects the sexual life of patients. Vitiligo of the face, head and neck significantly affects the QL regardless of the degree of disease progression. The quality of life is significantly reduced in women compared to men, as well as in cases where it covers more than 10% of the body surface (20). Women are more self-conscious about their disease than men, because it disrupts their social life, personal relationships, sexual activities, and the choice of clothes. A significant correlation exists between quality-of-life scores and patients' depression and anxiety (19,20).

DLQI scores tend to be lower in patients with vitiligo than in patients with psoriasis, because patients with vitiligo appear not to be better able to adapt to their disease and experience social discrimination compared with patients with psoriasis; however, the two groups did not differ in overall self-esteem scores. Patients often develop depressed feelings about their skin condition, which tends to be reinforced by social stigma. Many patients with vitiligo report feeling uncomfortable, which can lead to low self-esteem and social isolation (19,20).

Dermatology Quality of Life Index is the first dermatology-specific quality of life questionnaire developed in 1994, consisting of 10 simple questions translated into different languages. Scores range from 0 to 30 (0-1: no effect on patient's life, 2-5: small effect, 6-10: moderate effect, 11-20: very large effect, 21-30: extremely large effect) (21,22).

If we compare the research data with studies published from 1996 to 2012, the mean scores of the DLQI across the world ranged from 1.82 to 15, and the overall mean was 8.2, indicating a moderate effect of the QL (23,39).

QUALITY OF LIFE IN VITILIGO PATIENTS IN NORTH MACEDONIA

In 2021 in North Macedonia, we performed a prospective cross-sectional study consisted of 71 responders with vitiligo. This research is the first in North Macedonia that measures the quality of life in patients with vitiligo.

Methods: Two questionnaires were used. The Dermatology Quality Index Questionnaire

life from Cardiff University, UK with consent obtained from Prof. Finlay et al. in Macedonian language and the second questionnaire which contains the questions about demographic characteristics and disease activity.

All subjects/patients who met the selection criteria (adult, diagnose of vitiligo) were included in the study.

DLQI questionare includes 10 items about the patient's feelings and many aspects of the illness that occurred in the last 7 days. Questions include "vitiligo symptoms" (itching, pain, etc.) irritation), "feelings" (shame, anxiety and anger), "everyday activities" (shopping and activities in the home), "type of clothing", "social or leisure activities", "physical exercises", "educational activities", "sexual activities", "interpersonal relations" (with husband/s, friends, relatives) and 'treatment opportunities'. Each item is scored on a scale from four points (3 = a lot, 2 = moderately, 1 = a little, 0 = not at all).The total score of DLQI was calculated by summing the score of each of the 10 questions assessed and interpreted: as no impairment of quality of life (0–1), minor damage (2–5), moderate damage (6–10), severe damage (11–20), or a lot severe impairment (21–30).

In the second questionnaire, the data was filled by the researcher of the department of dermatology in PZU "Remedika" after a clinical examination of the patients and includes data on age, sex, place of residence, education,marital status, Fitzhaptrick skin type, comorbid diseases (hyperlipidemia, diabetes mellitus type 1, hyperthyroidism, hypothyroidism, pernicious anemia, alopecia areata, ophthalmic abnormalities), familial history of the disease, use of alcohol, cigarettes, BMI.

Data related to vitiligo include age at onset, family history of vitiligo, therapeutic history (with or without therapy), type of vitiligo (non-segmental, segmental and unclassified), vitiligo activity (in years), the natural flow (stable, unstable and with regression) and percentage of occupation of body surface. The localization and type of the disease were diagnosed with standard physical examination and using Wood's light. The percentage of skin area involved was calculated using the rule of nineundertaken by the Vitiligo European Task Force (VETF) (3,4).

Data analysis was performed in Statistica 7.1 for Windows and SPSS Statistics 23.0

Results

In this study we included 71 respondents, patients with vitiligo, who participated in the research, of which 38 (53.5 %) male and 33 (46.5%) female patients.

The total score for the DLQI ranged from 0 to 28 (from a maximum of 30 points), and the average was 11.70 ± 5.7 (Table 1).

Female patients have greater QL impairment (total mean value of 8.03) than men (5.99); there was a statistically significant difference between the results of the DLQI from both sexes (P = 0.019).

The total score, for quality of life, in terms of symptoms related to the condition of the skin in patients with vitiligo, in the six domains, strongly affects their quality of life in 45.1%.

The quality of life is significantly lower in the studied group of 16-30 years (13.85 ± 5.3) as compared to the population of 51-60 and over 60 years (6.75 ± 5.7, and 7.0 ± 2.3) in terms of daily activities and leisure activities and therapeutic treatment. As the age of patients with vitiligo advances, the quality of life improves.

Responders with higher education had a higher DIQS score (14.41 ± 6.6; p=0.001).

Table 1. Mean DLQI scores of the sample according to different heading items and rates of answers according to different bands of DLQI scores a Heading item

	mean ± SD	**min–max**	**95 % CI**
Symptoms and feelings	2,75 ± 1,4	0 – 6	1,2 – 1,7
Daily activities	2,51 ± 1,4	0 – 6	1,2 – 1,7
Leisure	2,13 ± 1,5	0 – 6	1,3 – 1,8
Work and school	1,14 ± 1,3	0 – 4	1,1 – 1,5
Personal relationship	2,04 ± 1,7	0 – 6	1,5 – 2,1
Treatment	1,15 ± 0,98	0 – 3	0,8 – 1,2
Total	11,70 ± 5,7	0 – 28	4,9 – 6,9

Patients in our study showed a moderate limitation of QoL, comparable to that of other chronic skin diseases.

Limitations of the study

Limitations of this study include a small study population, as well as possible selection bias as participating patients were recruited from a dermatology center in Remedika general hospital, Skopje N. Macedonia. Patients in our study showed a moderate limitation of QoL, comparable to that of other chronic skin diseases. Management should focus not only on medical treatment but also psychological aspects, hence better QoL and treatment outcomes.

Conclusion

Female patients with vitiligo have more impaired quality of life as compared to male patients with vitiligo. With age, the quality of life in patients with vitiligo improves. Patients with a lower degree of education have a better quality of life.

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