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## PSYCHOSOCIAL IMPACT ON A HEALTHY LIFESTYLE OF PATIENTS WITH VITILIGO AMONG THE POPULATION OF UZBEKISTAN

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### ABSTRACT

*Since patients with vitiligo in Uzbekistan have a relatively darker skin colour, the centre of depigmentation are more pronounced on darker skin, and this is an important factor associated with the disease. A survey of 50 patients was conducted to study how the disease affects the patient's social life, psychosocial status and healthy lifestyle.*

**KEYWORDS:** *Uzbek, Marriage, Profession, Psychosocial Impact, Vitiligo, Concern.*

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### INTRODUCTION

**Aim of the study:** This study was conducted to determine the causes of the disease, the concerns of the patients, their medical and psychosocial needs, treatment, the expected results of the healing doctor, and the psychosocial effects of the disease on the patient's healthy lifestyle.

### IMPORTANCE

Vitiligo is a chronic disease that is common among people and is accompanied by skin whitening (depigmentation). The origin of vitiligo is inextricably linked with the history of leprosy. In the past, patients with leprosy and vitiligo were kept separately in leprosy hospitals. Not being able to clinically differentiate between vitiligo and leprosy, the fear of white spots on the skin, causes various mental changes and patients' to be separated from the community.

By 1842, D. Danielson's scientific research ended word games in terminology. By 1873-1874, the Norwegian scientist A. Hansen proved that the causative agent of leprosy is mycobacteria and that this disease can only be transmitted from person to person. In this way, vitiligo and leprosy were recognized by scientists all over the world as separate diseases. But there is another side of the matter, why people still cannot distinguish between these two diseases.

0. 5%-1% of the world's population suffers from this disease, and the average age of onset is 24 years. Men and women also have the same rate of disease, regardless of skin type or race [5, 6, 7].

As people in our country are much dark-skinned, vitiligo is of special importance. Because white depigment skin is clearly distinguished from dark-coloured skin. Research conducted using tools

such as the dermatological index of quality of life (QOL), which assess health-related quality of life, has shown that vitiligo affects QOL [1], [2], [3]. For example, many studies have shown that mental disorders, such as stress, depression and sleep disorders, are manifested in a large number of patients. [4]. Other studies have proven the importance of appearance in psychological adjustment and the impact of depigmentation on physical impairment. [5], [6]. Vitiligo patients have lower self-esteem and confidence than the general population. [7]. Women with vitiligo are more likely to experience QOL disorders than men. [8]. Vitiligo has a disproportionately high psychosocial impact on children. [9]. Research conducted through questionnaires on QOL and mental illness in patients with vitiligo showed that mental disorders (depressive episodes, adjustment disorders, stress) were common in 25% of patients. [10], [11].

Many of these effects are caused by other serious skin conditions, and patients in other parts of the world have many of these problems, but the combination of individual, familial, and social attitudes to vitiligo place a particular burden on Uzbek patients with the disease. Studies of the burden of vitiligo usually use universal tools that have been developed in advance, and some issues that are particularly important for patients with vitiligo may not have been addressed.

We could not find any detailed research on the disease and its effect on healthy lifestyles in Uzbek patients. This study was conducted to determine the causes of the disease, aspects of the disease of concern, the medical and psychosocial needs of patients, treatment, the expected results of healing doctor, the impact of the disease on the patient's life, and the belief in the mechanisms used to cope with it.

In our study, information was obtained by conducting a semi-structured interview, which provides in-depth information about the patient's psychosocial depression and allows us to understand the subject's thoughts, feelings, and behaviours.

For such studies, purposeful sampling of patients is used, in which patients are selected who can fully express their thoughts and fully solve problems related to the disease. [12]. This research design has the advantage of being more dynamic, as the interviewer learns from the patient's responses, and as the learning continues, questions or different phrases can be added. It also allows for greater diversity in patient responses. [13]. It is clear that this study only provides complete information about the studied patients, but relative information about the population and the rest of the patients.

## **METHODS**

From July 2019 to April 2020, 50 patients who received outpatient and inpatient treatment at the Bukhara Regional Skin and Venereal Disease Dispensary were interviewed. Most of the visitors to our clinic are from the middle socio-economic class, mainly from the northern and southern regions of Uzbekistan.

The purposive selection was used because we wanted to assess the effect of psychosocial aspects on healthy lifestyles of patients with vitiligo onset at different levels and on a wide range of scales. Patients included men and women (married and unmarried), children (>12 years old), parents of children with vitiligo, elderly patients, recent disease (<6 months) and long-standing disease (>two years), limited vitiligo (<5%) and those with the disseminated type (> 10%), which included types found on non-visible parts of the body and genitals.

Patients who were able to fully describe their thoughts and experiences were interviewed. Interviews were conducted in one of the consultation rooms of the clinic with patient information kept confidential. Interviews were conducted based on a literature review guide and clinical experience. It consisted of questions about knowledge about the disease, psychosocial effects and coping mechanisms.

Probes for follow-up questions were created in the interview guide to explore the questions asked on the topic. The draft guideline was presented to three experienced dermatologists and suggested changes were made. During the interview, patients were given full opportunity to talk about their illness and additional information was obtained by asking relevant questions. Consent was obtained from patients and parents of patient children to participate in this study and to record the interview. 46 interviews were held in Uzbek and 4 in Russian. Each interview lasted about 40-50 minutes. The interview was stopped when the patient did not want to talk or when the questions in the manual were completely answered. Each interview was fully recorded. Those in Russian were translated into Uzbek. This process includes the steps of data familiarization, theme identification, sorting through written data and identifying evidence, selecting specific evidence and categorizing it into themes/categories, mapping, and final interpretation. The data were examined step by step to identify the participants' descriptions of their thoughts, feelings, and behaviours related to the topics mentioned in the interviews. After all, interviews were coded, general thematic data were combined and the following themes were identified: impact of the disease on healthy lifestyles, beliefs about vitiligo, concerns about the disease, issues related to treatment, and coping mechanisms.

## RESULTS

A total of 50 patients were interviewed. Patients were 31 men and 19 women aged 5 to 75 years, of which 16 men and 6 women were married. Interviews were held with the parents of 5 sick children. 5 patients only finished school. Most of the remaining patients have completed their studies (higher education) and 3 have master's degrees. Profession type of patients: engineering, pupil, student, health worker, accounting, marketing, farming, business, unemployed and housewife. Employed patients have a monthly income of 1.1 million to 6 million, the remaining 20 are students, 4 are unemployed, and 4 are housewives. The duration of the disease in patients is from 2 months to 12 years. White spots increased in 28 patients, and the process was stable in 22 patients. The mental status examination of all patients was within normal limits. In patients, white spots covered from 1% to 95% of the body surface. In 39 of the patients, it covered the damaged areas of the skin. In 9 patients, it appeared on the branches where the skin was not injured. It was present in the mucous membranes of 27 patients, of which it was present in the genitals of 18 patients. Patients had acrofacial (n=25), vulgar (n=10), focal (n=2), segmental (n=2), acrofacial and vulgar (n=8), mucosal vitiligo (n=1), universal (n=2) types were identified.

**Interview analysis.** The development of vitiligo can be related to nutritional problems, drug allergies, blood diseases, melanin deficiency, physical injuries, gastrointestinal and liver problems, climatic conditions (atmosphere, water), chronic diseases, infectious diseases, stress and depression. The disease was not considered by many to be contagious, hereditary, and related to leprosy, but some did not, and this led to stigmatization. Some patients report that their friends and relatives believe these misconceptions; even if they don't. The first reaction of patients to the appearance of vitiligo would be to ignore it as much as possible. They were given reasons such as allergies, dry skin, leprosy, mineral deficiency, worms, fungal skin diseases,

burns, wounds and insect bites. Vitiligo is a serious disease due to its negative impact on life and work, feelings of inferiority, resistance to treatment and exposure to sunlight in depigmenting skin. Those who said it was not a serious disease noted that the disease was asymptomatic, non-contagious, effective in early treatment, not leprosy, and no one had a negative reaction to the spots. Dietary restrictions were repeated frequently. Avoided from various food items like sour food, non-vegetarian food, milk/curd, excess bitters/spices, alcohol, oil, uncooked food, sweets, rice, tea, wheat pastry, green vegetables, and fish. Other restrictions include wearing synthetic and cotton clothing and shoes made of rubber or plastic materials. Patients wore clothing that covered their vitiligo areas. Various alarming cases of the disease have been reported. Patients were dissatisfied with their appearance and seriously lowered their self-esteem. The disease caused anxiety, depression and low self-esteem. Over time, these concerns subsided and they accepted it. A few patients admitted that they sometimes had suicidal thoughts, but none attempted suicide. Some patients thought about vitiligo all day, some looked at the mirror repeatedly, and some did not pay attention at all. Parents of children with vitiligo have always thought about this disease. They thought a lot about the fact that the disease would cause serious problems for their children to have a family.

On the contrary, the anxiety of parents has a strong influence on the minds of their children; the disease caused less concern than the anxiety and unhappiness of the parents. At school or college, patients had difficulty in participating to various activities, preferred to study part-time whenever possible, missed classes due to constant doctor visits, and were teased by other students. Problems were less common in workplaces. A few patients faced a number of problems in getting a job and were not allowed to pursue the profession they wanted. Due to illness, they had to look for other professions. Patients had difficulties in starting a family, women more than men. This was a greater problem for patients living in rural settings. One patient said that he had been rejected four times because of this disease. In some cases, after noticing the symptoms of the disease in the patients, their parents, fearing the spread of the disease, forced them to start a family as soon as possible, regardless of their age. The illness was kept a secret until the time of marriage due to embarrassment and fear of rejection. Also, some patients believe that it can be transmitted by sexual intercourse. One patient said that her mother-in-law would divorce her with his son if she did not get treatment for her illness. A woman with vitiligo on her chest had problems because her husband was uncomfortable during sex. Another major concern was disease progression.

Although the disease was located in invisible areas of the body, patients were afraid of drawing attention to others because of their skin. Another concern is the greying of the hairs in the area of the white spots, not wearing revealing clothes and being exposed to pathetic situations. Most of the patients received adequate encouragement from their family members, including moral support, financial support for treatment, and companionship from family members. This gave them great comfort. However, many patients felt guilty and feared that the disease would spread to family members or affect other family members' marriages. Patients with visible scars severely limit social activity and meeting people because of their shame. People's comments about their scars prevented them from shaking hands with others. They have difficulty or are tired to answer various questions. One patient did not visit his sister because he was afraid that her family would be disturbed if they found out that her brother had a spot. Due to this disease, two of our patient's lives were disrupted. In our patients, the spots were located in invisible areas of the body and did not have social difficulties. Patients turned to alternative medicine, healers,

and other practitioners of the local medical system in search of cures. These were believed to have no side effects. Dietary and lifestyle restrictions are often recommended by alternative and indigenous medicine practitioners and dermatologists.

Vitiligo treatment has been a financial challenge for some of our patients. Many doctors were consulted for treatment, the maximum number of them was 20. Patients who presented for the first time had relatively less information about the disease and had fewer misconceptions than those who had been talking about the disease for a long time.

**Treatment issues.** Patients wanted complete treatment. When asked what level of improvement is possible if full recovery is not possible, many patients say that they are satisfied if the spots do not spread to other areas or increase in size. Repigmentation and varying degrees of regeneration were desired in damaged skin (such as on the hands and feet). Some have said that they are not at all satisfied if their skin colour is not completely restored. There were those who were older than 50 and married with children who did not feel the need for treatment.

**Disease coping mechanisms.** Patients used several coping mechanisms when thinking about their illness. Patients distracted themselves by praying or listening to music, watching television, reading books, playing games, or doing tasks related to their daily work and job. Other mechanisms were to talk to their family members, friends, or doctors, or to seek information from different sources in search of a cure. Patients with unsuccessful coping mechanisms had crying spells, persistent depressed mood, isolation from the community, persistent thoughts about the illness, engaging in unhealthy habits, and suicidal thoughts.

## DISCUSSION

Our study shows how it affects the lives of Uzbek patients with vitiligo. Despite the different upbringing, scientific and spiritual levels and professional backgrounds, the patient's concerns and beliefs were similar, and misconceptions about vitiligo were ingrained in all social classes. In addition to being separated from society, patients with vitiligo also felt guilty that their disease had affected non-diseased family members. Several studies have reported lower self-esteem in patients with vitiligo [7], and those who completed a better coping mechanism for the defect had higher self-esteem. [6]. Some patients thought about their illness all day and could not bear to look at themselves in the mirror, even when the closed parts of the body were affected. Based on a previous survey and interview, many patients indicated that they were concerned about the spots spreading throughout the body, the disease being passed on to their children, and whether new treatments would be found. More than half of them said that people were staring at them, and 20-25% of the patients said that they were mentally tormented by the words spoken by strangers. [6], [14]. Another study found that 10% of 30 patients had depression, one had anxiety, one had depression, and one had a suicidal idea. [4].

The concern that the disease might spread throughout the body was an important reason for seeking treatment. Psychosocial effects on education, life and professional activities are felt more by patients of marriage age. In elderly patients, the difficulties in the social and spiritual life of young family members who were not ill caused more concern. Vitiligo is seen as having careers and being denied employment. On the other hand, it may have less influence on the development of the disease after employment. A strong sphere of influence is the difficulties encountered in marriage. Even after marriage, vitiligo continues to take its toll, leading to inbreeding, sexual



difficulties, and even divorce. Patients also faced difficulties due to unsolicited advice and various questions from family members, peers and friends.

In a study conducted by Ongenae and others (3), it was found that the location of vitiligo on the head, neck, arms, and legs affected the overall DLQI scores. Vitiligo patients were exposed to social problems, but the majority of patients noted that they were indifferent to these problems. While patients with invisible illnesses were less concerned about social impact and functioning, they were more concerned about the spread of the disease and its social consequences. DLQI indicators were often higher in patients who were referred to a dermatologist for their diseases [3]. Our study required rapid treatment results, resulting in multiple consultations and high costs. Treatment should have resulted in complete repigmentation or at least termination of disease progression. Patients often changed their doctors due to a lack of information about long-term treatment, very low efficacy after each course of treatment and patient impatience. Dietary restrictions are believed to play an important role in the treatment process by patients, their families, and physicians. Over time, less concern with illness emerged, but this was not an irreversible change in attitudes. For example, patients who were not bothered by their disease and did not want treatment began to worry about the disease when they were discharged for medical reasons due to vitiligo. The ability to handle responsibility is related to the level of self-awareness. Patients with a positive self-image are able to overcome mental and physical deficits [15]. Patients with poor coping mechanisms are more distressed about their illness than those with other coping mechanisms. This is very important in treatment, as these patients need to be taught disease-fighting mechanisms in addition to treating white spots. The limitations of our study are that we selected patients on purpose (it is not possible to conduct such questionnaires on all patients in general), so the results may not be applicable to all patients with vitiligo. However, the observations made in this study are important for treating vitiligo and preventing depression. In addition to the primary dermatologic condition, assessment of psychological and social factors is more likely to be associated with vitiligo than with other skin conditions [16]. Interestingly, less positive treatment efficacy was found in patients with poorer quality of life. [17,18,19,20]. In assessing the psychological impact of vitiligo, the patient's life situation, including the attitude of social support colleagues and family members, is also important, because even a mild disease can cause severe distress to the patient. Psychological interventions, such as cognitive behavioural therapy, can help improve body image, self-esteem, and QOL and have a positive effect on the course of the disease in patients with vitiligo.

## CONCLUSION

Addressing psychosocial factors is an important aspect of vitiligo treatment and healthy living, especially for patients in communities that tend to be socially excluded.

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