Self-esteem in people with acquired vitiligo. A survey-based study

Poczucie własnej wartości u osób z bielactwem nabytej. Badanie ankietowe

ABSTRACT

Vitiligo is a skin disease characterized by loss of skin pigmentation, visible in the form of bright white patches distributed on the surface of the body. It can be congenital (hereditary) or acquired.

The aim of this study was to assess the self-esteem of people with acquired vitiligo. The study was based on an anonymous questionnaire completed by 195 participants.

The majority of the respondents indicated that the placement of the skin abnormalities was a cosmetic concern, and that vitiligo affected their self-acceptance and contributed to their diminished emotional state. In their opinion, stress of daily life can influence the appearance of new vitiligo lesions or increase of already existing skin discoloration. Although vitiligo brings many challenges for the majority of respondents, they maintain that it has a minimal impact on their overall quality of life.

Keywords: skin, acquired vitiligo, self-esteem, stress, quality of life, DLQI questionnaire

STRESZCZENIE

Bielactwo to choroba skóry objawiająca się utratą pigmentacji skóry, widoczną w formie jasnych, białych plam rozmiarowych na powierzchni ciała. Może mieć charakter wrodzony (dziedziczny) lub nabyty.

Celem pracy była ocena poczucia własnej wartości osób z bielactwem nabytem. W przeprowadzonych badaniach wykorzystano anonimową ankietę, w której udział wzięło 195 osób.

Większość ankietowanych twierdzi, że lokalizacja zmian stawia dla nich problem natury estetycznej oraz że bielactwo utrudnia im samoakceptację i jest powodem obniżonego nastraja. Ich zdaniem, stres związany z codziennym życiem może mieć wpływ na pojawianie się nowych zmian bielaczych lub zwiększanie się już istniejących odbarwień skórnych. Mimo trudności, które dla większości badanych niesie ze sobą bielactwo, uważają, że nie wpływa ono istotnie na ich jakość życia.

Słowa kluczowe: skóra, bielactwo nabyte, poczucie własnej wartości, stres, jakość życia, kwestionariusz DLQI

INTRODUCTION

Vitiligo is a skin disease (dermatosis) that affects approximately 0.5-2% of the population, regardless of gender or ethnic group, and is based on the phenomenon of melanocyte destruction [1].

The most common distinctions are between acquired and congenital vitiligo.

• Congenital vitiligo is caused by genetic factors and involves a complete lack of melanin in the skin, its appendages and all cells of the body. It is otherwise known as albinism.

• Acquired vitiligo is manifested by the development of patchy skin colouration, including the appearance of hypopigmented patches. Approximately half of people with vitiligo have acquired skin lesions between the ages of ten and thirty, with an average onset at around 20 years old [1]. Statistics show that vitiligo appearing as early as childhood, i.e. under 10 years of age,
accounts for as many as 25% of all cases and manifests itself between 4 and 8 years of age [2].

Acquired vitiligo, although not a life-threatening disease, can cause many problems in the psychosocial sphere of the individual. People affected by vitiligo often perceive the existing lesions as a defect or blemish on their skin. In addition, the prevalence of lesions on exposed parts of the body makes it more difficult for them to accept the condition.

Cases of depression have been reported in 55% of patients with acquired vitiligo, and patients themselves perceive lowered self-esteem, increased feelings of stress and discrimination in their environment [3].

The media is increasingly covering issues of discrimination against people with vitiligo. Social initiatives are promoting the idea that otherness can be regarded positively, hence increasing awareness. Nevertheless, the sense of rejection and underestimation of self-worth among people affected by vitiligo is a real issue that society should be aware of.

This article focuses on the assessment of the self-esteem of people with vitiligo. It consists of a variety of factors, closely related to the individual’s social situation, such as self-acceptance, self-esteem, self-respect and dignity, as well as feelings of interacting society.

MATERIALS AND METHODS
The research employed an anonymous questionnaire. The survey was conducted by administering it to participants through Google Form. Details regarding the ability to participate in the questionnaire were shared on Facebook within a private group called “Vitiligo - advice and support,” which is specifically designed for people with vitiligo.

The main survey was preceded by a pilot study on 26-28.04.2023, with a group of 10 people. After analysing the data, it concluded that no modifications need be made to the questionnaire. After the main survey was conducted on 3-20.05.2023, 195 responses were received.

The survey of 35 questions was categorised into three sections: information, research, and metrics. Among these, nine questions were generated from a quality of life questionnaire that evaluated the influence of skin problems on the patient’s well-being (DLQI, Dermatology Life Quality Index).

The DLQI questionnaire was developed by Prof Andrew Y Finlay and Dr Gul Karim Khan in 1994 as one of the first tools to measure quality of life in dermatology. The DLQI measures the impact of a dermatological condition on an individual’s quality of life by referring to how it has affected their feelings, symptoms and impact on their daily life, personal and professional, over the past week.

The survey questionnaire primarily consisted of closed questions, where respondents were required to choose the most accurate answer from a predetermined list of options. Four open-ended questions were given to allow participants to provide their own response.

RESULTS OF THE STUDY
In order to characterise the group of people studied, the questionnaire included questions about their age, the gender with which they identify, their education, their marital status and their place of residence.

The information gathered from the responses showed that the respondents were mostly women (81%) in the age range 30-39 years (33%) and 20-29 years (32%) and 40-49 years (22%), with higher (57.6%), secondary (33%) and postgraduate (6.3%) education (Fig. 1). The smallest percentage point difference, was noted when analysing the responses regarding marital status. 30% of respondents indicated that they were single and 26% were in an informal relationship, with the majority (43.5%) responding that they were in a formalised relationship. At the same time, only 31.3% of respondents felt that their life partners supported them in coming to terms with vitiligo and living with it on a daily basis.

The group of people surveyed varied by place of residence: 34.7% came from cities with more than 150,000 inhabitants, 17.6% from cities with 50-150,000 inhabitants, 21.8% from cities with up to 50,000 inhabitants and 25.9% from rural areas.

Other questions focused on vitiligo itself and how people with this skin dysfunction cope with the difficulties of everyday life. Out of the 195 individuals polled, 38.7% have co-morbidities such as Hashimoto’s disease, while up to 26.3% have not undergone any testing to determine if they belong to this group.

The number of people who were diagnosed with vitiligo was as follows: 59.3% of respondents were first diagnosed at 11-19 years, 32% at 20-29 years and 20-39 years, and 10.5% at 40-49 years.

Cases of depression have been reported in 55% of patients with acquired vitiligo, and patients themselves perceive lowered self-esteem, increased feelings of stress and discrimination in their environment.
The vast majority of respondents (83.5%) described the time they had been diagnosed with vitiligo as longer than five years, with 47.3% saying they had been struggling with it for more than 10 years (Fig. 2).

The participants who have vitiligo lesions reported that these lesions are predominantly found on the hands, intimate areas, and face (Fig. 3). These areas are frequently highly noticeable, and as a result, deviating from the socially accepted standard can be linked to stigma or rejection and serve as a cause for psychological insecurities. Aesthetic concerns regarding the location of the lesions were reported by a significant majority of respondents, specifically 77.1%.

Among a comparable number of participants, a significant proportion experienced psychological distress due to the presence of vitiligo spots. Specifically, 53.4% of respondents reported that vitiligo hindered their self-acceptance and contributed to a decrease in their overall mood. This sentiment was expressed by 25.4% of participants who answered “definitely yes” and 28% who answered “rather yes” (Fig. 4).

Simultaneously, a minority of the participants (44.1% in total, with 16.6% responding definitely yes and 27.5% responding rather yes) expressed that having blemishes hinders their ability to engage with new people.

The vast majority tried to treat their vitiligo (85%), but abandoned the treatment and did not undergo any treatment (78.1%). 77.7% of respondents state that the treatment was not effective and they did not experience an improvement in their quality of life.

The study also examined the therapeutic techniques employed by the participants and determined which of those methods yielded the highest level of satisfaction with the outcomes. The skin improvement question also included choices for respondents to consider their own efforts, such as psychological therapy, stress reduction, and a change in attitude towards the disease. 48.1% of the participants reported that lowering stressors in their everyday life was beneficial, while 41.2% indicated that adopting a positive attitude towards the disease was the second most common approach (Figure 5).

These responses are consistent with the findings of the subsequent question in the poll. Participants were requested to evaluate whether they believed that the pressures of daily living influenced the occurrence of new or the growth of existing vitiligo patches. The findings revealed that a significant proportion of the participants, up to 69.6%, responded positively, whilst only 10% expressed a negative response.

The respondents’ current attitude towards the disease and if they experienced any social exclusion due to their acquired vitiligo were...
particularly intriguing. In the inquiry regarding attitudes towards the disease, respondents were provided with the opportunity to provide an open-ended response in addition to the closed-ended options. These comments revealed a pessimistic outlook towards the condition, expressed not by the patients themselves, but by their close relatives. 73.7% of the respondents indicate that they have reconciled with having vitiligo, whereas only 37.7% of them have truly embraced it.

In the context of the question concerning exclusion and behaviours that cause respondents to feel stigmatised, the largest number of responses referred to the subjective feeling of unfavourable stares from those around them, especially when respondents exposed the white spots on their skin (57.3%). Another common response in this context was to indicate appropriate comments from those around them and direct questions about respondents’ attempts to erase their white spots. Respondents who pointed this answer also indicated that their surroundings had let them know that they considered the stains unsightly (30.8%).

The respondents emphasised the unfavourable disposition and absence of acknowledgment towards their vitiligo by their immediate social circle, particularly older individuals within their families, with a particular emphasis on their parents.

However, a significant proportion of respondents (62.1%) did not perceive themselves as being impacted by ostracism, whereas only approximately 17.6% of respondents expressed a tendency towards acknowledging its presence.

However, the allocation of votes varies in the question about respondents’ encounters with exclusion as a result of vitiligo during their youth. As many as 45.5% believe that rejection from their environment at a young age significantly affected, not only their relationships with their peers, but also those in later stages of life. At the same time, 40% denied this statement (16.2% answer no and 23.8% rather not). Additionally, it is noteworthy that 34.1% of participants selected the ‘not relevant’ choice, which was specifically designed for individuals who either developed vitiligo in maturity or have experienced a brief illness.

The final questions from the DLQI questionnaire aimed to find out how respondents rated their quality of life due to their vitiligo. The responses from this questionnaire are presented collectively in the graph (Figure 7).

**DISCUSSION**

The symptoms of vitiligo are caused by the death of melanocytes, however the exact cause of the disease is not yet entirely understood. Nevertheless, there exist hypotheses regarding the underlying factors responsible for the occurrence of vitiligo [4]. One of these theories is the autoimmune theory. This is based on the assumption that the demise of melanocytes is caused by substantial immunological problems. This theory emphasises the association between the presence of vitiligo and autoimmune diseases in patients, such as Hashimoto’s disease, ocular disorders (uveitis, retinitis pigmentosa), Addison’s disease, Graves- Basedow disease, type 1 diabetes, psoriasis, and inflammatory bowel disease [5]. According to a study reported in 2016, it was shown that between 14.4% and 25% of individuals with vitiligo also had at least one autoimmune co-morbidity. This frequency is quite important, as it is below 6% compared to the overall population. In the meantime, blood tests revealed a significantly higher occurrence of antibodies targeting melanocyte proteins in individuals with vitiligo [6].

An additional indication in favour of the immune theory was confirmed by a 2005 study described by Mason and Gawkrodger. They stated that activated, autoreactive CD8+ T lymphocytes, or cytotoxic T lymphocytes, were found in the skin from around the whitehead lesions [7]. These lymphocytes play a very important role in the body’s immune responses. Their function is to recognise and induce apoptosis in virus-infected and
tumour cells. However, in cases of autoimmune diseases, antibodies against melanocyte proteins are observed in concentrations above normal, e.g. systemic lupus erythematosus, scleroderma and multiple sclerosis [8], but also in active tumour conditions and in elderly patients [9].

Another theory is the oxidative stress concept, which suggests the involvement of free radicals in the initiation of melanocyte destruction. The theory is based on the belief that in vitiligo patients the functioning of the antioxidant system in melanocytes is impaired. During the melanin production process, the metabolism of individual products and substrates is impaired, which, becoming metabolites of this chain reaction, have toxic effects on the body’s cells. These include dihydroxyindole (DHI), which is a dihydroxyl derivative of indole, and L-Dopa, which is a catecholamine formed by hydroxylation of L-tyrosine. The lack of elimination of the above-mentioned intermediate compounds by metabolising them to DHI-melanin (the dark-coloured component of eumelanin) and DOPA quinone (an amino acid having benzoquinone in its side chain) results in the accumulation of hydrogen peroxide \( (\text{H}_2\text{O}_2) \) in later stages, leading to oxidative stress. The accumulation of \( \text{H}_2\text{O}_2 \) itself, with the occurrence of an undersupply of catalase, can then lead to a decrease in the concentrations of the enzyme tyrosinase and thus cause further disruption of melanin production [10].

An important aspect of the presented study was the concept of self-esteem in people with acquired vitiligo. These individuals face a great deal of rejection from their environment. Until recently, in first-world countries, they were ostracised and their vitiligo lesions were regarded as unsightly and undesirable on the skin. To this day, in third world countries, people with acquired vitiligo as well as congenital vitiligo in particular are rejected from societies, condemned to banishment or murdered because of their affliction [11].

In order to discuss self-esteem more broadly and to understand how it develops in people with acquired vitiligo, it is important to define the concept of self-esteem itself.

As Niebrzydowski and Branden explained, it was a kind of collective term for self-esteem, self-acceptance as well as self-respect and dignity. They put it as “an immune system of consciousness that not only determines the strength of survival, but also the individual’s capacity for self-control and self actualisation” [12]. This term contains an allegorical comparison to the body’s immune system, but the authors here meant the immune system of the human psyche. They thus stated that without self-acceptance, we are unable to develop and operate efficiently in society.

In his analyses, Branden additionally distinguished the components that, according to him, shape self-esteem [13]. He draw attention to self-efficacy and self-esteem. He described these as a belief in one’s own abilities when dealing with everyday challenges, emphasising that it was linked to self-trust and confidence in one’s own abilities. A sense of esteem and a perception of one’s self as a valuable individual capable of achieving success, fulfilment and happiness were also integral to this process.

In addition, Niebrzydowski suggested that self-acceptance is a necessary condition for establishing healthy relationships [14]. It develops a favourable self-perception and serves as both an initiator and an accelerator, enabling individuals to freely engage in social endeavours and pursue new ventures.

The presented approaches to self-acceptance seem to be the most appropriate and having in mind all areas of self-esteem, i.e. self-assessment, self-acceptance, self-awareness and dignity. The authors of the study, based on the analysis of responses regarding complexes and barriers of people with hypopigmented skin patches, note a significant underestimation of self-acceptance among the respondents.

As described by Goralewska, a sense of self-acceptance correlates with an increased lack of motivation to undertake the activities of daily living and the challenges posed by the individual, and consequently a low amount of success in achieving the goals set for oneself [15].

Self-esteem is not only a substantively very complex concept, but in practice it also manifests itself as an intricate network of closely interconnected beliefs of the individual concerning himself and the surrounding environment. This fact must not be forgotten when analysing the results obtained in the survey, which do not seem obvious at first glance.

When observing the social media interactions of the study group members, it was noted that there were repeated requests from participants to help ‘fight the spots’. These were argued on the basis of the embarrassment associated with exposing areas covered by whitish lesions. These observations are in line with the results obtained in the study.

In the group analysed, it can be noted that, despite having experienced vitiligo for a long time, about half of the people experience feelings of embarrassment about the state of their skin, which influences their daily choice of clothes. At the same time, the answers to the other questions confirm the researchers’ concerns about the respondents’ complexes and lowered sense of self-acceptance and aesthetics regarding the appearance of their skin.

The researchers observed a significant discrepancy between the results obtained from the aforementioned questions and the data from the DLQI questionnaire. Despite the respondents’ perceived embarrassment related to their skin condition, they rated the quality of life itself as very good. The percentage of people who indicated vitiligo as a major problem in their daily professional, social and intimate life was less than 9%.

The above-described positive results from the DLQI questionnaire seem to contradict the survey results, which had negative overtones. This could lead to the hypothesis that a kind of cognitive dissonance [16] or repression [17] of
the respondents’ negative feelings towards themselves was observed during the survey. Such a discrepancy may have been due to the fact that the survey contained simple questions that did not require deep thinking about the answer, whereas the DLQI questionnaire engaged the respondents in analysing their own behaviour and experiences. The described way in which the questions were framed, both in the survey and DLQI questionnaire sections, and juxtaposed with each other, may have been problematic and ambiguous for the respondents.

Additionally, after observing the social media interactions of the study group and comparing these observations with the survey results, it can be seen that the majority of the study participants are individuals characterised by deficits in self-acceptance. For some of these personalities, these deficiencies started as early as childhood. However, there is also a subgroup that actively seeks to improve their mental health.

This observation about the group studied supports the hypothesis of cognitive dissonance among the respondents put forward above, but it is not possible to confirm it on the basis of the research carried out and described in the work above. It is therefore necessary to continue research on self-esteem among excluded people in order to be able to analyse in more detail the specificity of the problems they face on a daily basis.

It is worth emphasising that the results obtained relate only to the people who took part in the study. Due to the limited size of the study group, these results should not be generalised to the entire community of people with acquired vitiligo. However, it is important to take them into account and strive to improve the quality of life of people with vitiligo by working on strengthening their self-esteem.

CONCLUSIONS

1. The majority of respondents confirmed the presence of complexes and lowered self-esteem in themselves due to active vitiligo lesions.

2. The vast majority of vitiligo patients believed that increased stress in daily life promotes the appearance of new outbreaks of vitiligo lesions.

3. Despite the difficulties associated with vitiligo, the majority of respondents felt that it had a minimal impact on their quality of life.

REFERENCES / LITERATURA