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LIVING WITH VITILIGO: IMPACT OF THE DISEASE ON THE INDIVIDUALS' QUALITY OF LIFE

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ABSTRACT

Introduction: Vitiligo is a disease characterized by asymptomatic hypochromic and/or achromic macules, localized or generalized in the integumentary system. The visible depigmentation in the skin of the individual and usually exposed in daily life changes the body image, impacting their quality of life. **Objective:** To evaluate the quality of life of people living with vitiligo. **Method:** This is a cross-sectional study carried out with 86 individuals with vitiligo. For data collection, the Vitiligo-Specific Quality-of-Life Instrument questionnaire was used for quality of life. **Results:** Adult women (81.4%) (mean age 39 years old) with vitiligo had a medium impact on quality of life, and the factors that interfered with quality of life are related to intensified skin care, progression, and appearance of the disease. **Conclusion:** The vitiligo pathology interfered in the quality of life of adults. The factors that impacted quality of life were intensified skin care in leisure activities, the progression of the disease and the appearance of hypochromic spots.

DESCRIPTORS: Vitiligo. Quality of life. Nursing. Enterostomal therapy.

CONVIVENDO COM O VITILIGO: IMPACTO DA DOENÇA NA QUALIDADE DE VIDA DAS PESSOAS

RESUMO

Introdução: O vitiligo é uma doença caracterizada por máculas hipocrômicas e/ou acrômicas assintomáticas, localizadas ou generalizadas no sistema tegumentar. A despigmentação visível na pele do indivíduo e, usualmente, exposta no cotidiano altera a imagem corporal, impactando na sua qualidade de vida. **Objetivo:** Avaliar a qualidade de vida das pessoas que convivem com o vitiligo. **Método:** Trata-se de um estudo transversal realizado com 86 indivíduos com vitiligo. Para a coleta de dados, utilizou-se o questionário *Vitiligo-Specific Quality-of-Life Instrument* para a qualidade de vida. **Resultados:** As mulheres (81,4%) em idade adulta (média de 39 anos) com vitiligo apresentaram médio impacto na qualidade de vida, e os fatores que interferiram na qualidade de vida estão relacionados aos cuidados intensificados com a pele, à progressão e à aparência da patologia. **Conclusão:** A patologia vitiligo interferiu na qualidade de vida dos indivíduos adultos. Os fatores que impactaram na qualidade de vida foram os cuidados intensificados com a pele em atividades de lazer, a preocupação com a progressão da doença e a aparência das manchas hipocrômicas.

DESCRITORES: Vitiligo. Qualidade de vida. Enfermagem. Estomaterapia.

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VIVIR CON VITÍLIGO: EL IMPACTO DE LA ENFERMEDAD EN LA CALIDAD DE VIDA DE LAS PERSONAS

RESUMEN

Introducción: El vitíligo es una enfermedad caracterizada por máculas hipocrómicas y/o acrómicas asintomáticas, localizadas o generalizadas en el sistema tegumentario. La despigmentación visible en la piel del individuo y, generalmente expuesta en la vida diaria, cambia la imagen corporal impactando en su calidad de vida. **Objetivo:** Evaluar la calidad de vida de las personas que viven con vitíligo. Método: Se trata de un estudio transversal realizado con 86 individuos con vitíligo. Para la recolección de datos se utilizó el cuestionario Vitiligo-specific Quality-of-Life Instrument (VitQol) para la calidad de vida. **Resultados:** Las mujeres adultas (81,4%) (edad media 39 años) con vitíligo tuvieron un impacto medio en la calidad de vida y los factores que interfieren en la calidad de vida están relacionados con el cuidado intensificado de la piel, la progresión y aparición de la patologia. **Conclusión:** La patología vitíligo interfirió en la calidad de vida de los adultos. Los factores que impactaron en la CV fueron el cuidado intensificado de la piel en las actividades de ocio, la preocupación por la progresión de la enfermedad y la aparición de manchas hipocrómicas.

DESCRIPTORES: Vitíligo. Calidad de vida. Enferméria. Estomaterapia.

INTRODUCTION

The skin is the largest organ of the human body and acts as a physical barrier, protecting it against harmful external damage. It has different functions, such as thermoregulation, hydroelectrolytic balance, vitamin D synthesis and sensorial stimulation[1]. There are several pathologies that can damage the skin, among them vitiligo.

Worldwide, the prevalence of vitiligo permeates from 0.75 to 1.1% of the adult population; 40% of them are believed to be undiagnosed[2]. In Brazil there are few studies that address epidemiological data of the disease, especially in adults. To this end, the Brazilian Society of Dermatology carried out a study to investigate its prevalence, and the results showed that 0.5% of the Brazilian population is diagnosed with vitiligo[3].

Vitiligo is a chronic, multifactorial, systemic pathology that has a randomized clinical course. It can be classified as an autoimmune disease, usually triggered by stress factors[4,5]. The disease is characterized by hypochromic and/or achromic macules, localized or generalized on the integumentary system, especially on the eyes, nose, eyebrows, elbows, and fingers. It is caused by skin depigmentation due to the loss or gradual absence of melanocytes in the affected area[4,5].

The depigmentation visible on the individual's skin and usually exposed in everyday life alters the body image and gives rise to a mistaken perception by society. This stigma arouses feelings of anxiety, sadness, anguish, social isolation, and anger[6,7]. The physical and psychological changes caused by the presence of vitiligo exacerbate disorders such as self-confidence, insecurity, shame, isolation and even depression, directly impacting on the worsening of their quality of life (QoL)[8].

Quality of life is defined by the World Health Organization (WHO) as an individual's "perception of his position in life in the context of the culture and value system in which he lives and in relation to his goals, expectations, standards, and concerns"[9].

In this context, any pathophysiological change in the skin can compromise the QoL, because culturally the integument represents identity in the face of the external environment, symbolizes individual satisfaction and self-confidence. Therefore, it becomes an indicator of physical and mental well-being of the whole humanbeing[10].

Therefore, recognizing the scenario in which individuals are allocated, as well as the negative impacts of vitiligo in their daily lives, is fundamental, as it allows the professional to provide particularized assistance. Despite the representativeness of the disease in Brazil, there are insufficient studies addressing the analysis of QoL in adults with vitiligo.

Therefore, the treatment of vitiligo becomes a therapeutic challenge, because it requires a general understanding of the psychological and physical relationship in the disease health process. Interventions should be immediate at any stage and address the triggers of worsening QoL, focusing on individual-centered care rather than the disease[10]. Thus, the objective of this study was to evaluate the QL of people living with vitiligo.

METHODS

This is a cross-sectional survey conducted from January to March 2021. A total of 86 individuals with a medical diagnosis of vitiligo participated in the research.

For data collection, the following inclusion criteria were considered: medical diagnosis of vitiligo, age over 18 years, and both genders. People with cognitive impairment were excluded from the studies.

To reach the target audience, the approach was taken in an online manner, because of the global pandemic scenario. Thus, for health security purposes and for social distancing, the survey took place via the Google Forms platform.

Participants were selected by digital invitation in social networking groups concerning vitiligo. After the invitation, they were informed about the objective and, if they accepted, they were given the informed consent form (ICF).

For data collection, two instruments were used. The first questionnaire was related to social and health variables, constructed by the researchers to characterize the sample. The second, for the assessment of QoL, is called Vitiligo-Specific Quality-of-Life Instrument (VitQol)[11]. The instrument with social and clinical data is composed of the variables: age, sex, marital status, and income, while the clinical data consists of time of diagnosis and treatment performed.

The VitQol instrument was adapted and validated for Brazil in 2016. It consists of 16 questions, which analyze how much the skin has affected the individual in the last month. The responses range from 0 (not at all/not applicable) to 6 (very). The final score is computed by means of the averages of the answers, ranging from 0 (optimal QL) to 90 (worst QL).

The collected data were stored in the Microsoft Office Excel program, version 2019. The data treatment was done by calculating the absolute and relative frequencies for categorical variables and the mean for continuous variables.

The study followed the ethical precepts, respecting the legislation established regarding research with human beings, determined by Resolution No. 466/12, of the Brazilian Ministry of Health. Data collection began after approval by the Research Ethics Committee, with Certificate of Ethical Appraisal Presentation number 44878821.6.0000.5158, from the Universidade Vale do Rio Verde.

RESULTS

A total of 86 individuals with a medical diagnosis of vitiligo participated in the research. Regarding personal data, the female gender prevailed, represented by 81.4%, also monthly income of R$1,500 to 2,000 (36%), married (47.7%), and average age of 39 years, as shown in Table 1.

Table 2 presents the clinical information. Of the participants, 72.1% reported prior knowledge of the disease and received the diagnosis at the average age of 20 years. Of the total, 32% emphasized that they suffered prejudice, but 89.5% received family support.

Regarding the QoL in people with vitiligo, the average score was 56.7, in a total score ranging from 0 to 90. Among the factors that negatively interfere the QoL, intensified skin care during leisure activities, such as protection and limitation of exposure to ultraviolet rays, stand out (4.8). Furthermore, concern about the progression of the disease (4.8) and the appearance of the hypochromic patches (4.5) had the worst scores, as shown in Table 3.

When asked about the perceived severity of the skin alteration, the respondents considered it to be severe (4.5), a score ranging from 0 (no skin involvement) to 6 (worst case).

Table 1. Social data of people with vitiligo (n = 86).

Variable	Absolute frequency	Relative frequency (%)	Average
Age			39.09
Sex			
Male	16	18.6	
Female	70	81.4	
Income (R$)			
< 1,000	24	27.9	
From 1,500 to 2,000	31	36	
> 2,000	31	36	
Marital status			
Single	30	34.9	
Married	41	47.7	
Divorced	8	9.3	
Others	7	8.1	

Source: Elaborated by the authors.

Table 2. Clinical data from people with vitiligo (n = 86).

Variable	Absolute frequency	Relative frequency (%)	Average
Did you already know vitiligo?			
Yes	62	72.1	
No	24	27.9	
At what age was the diagnosis?			20.3
Did you have family support?			
Yes	77	**89.5**	
No	9	10.5	
Have you suffered prejudice because of the disease?			
Yes	56	**65.2**	
No	30	34.8	
Treatment			
Yes	28	32.6	
No	58	**67.4**	
Do you use any method to hide the patches?			
Yes	36	**41.9**	
No	50	58.1	
Quality of life			56.7

Source: Elaborated by the authors.

Table 3. Quality of life of people with vitiligo (n = 86), Vitiligo-Specific Quality-of-Life Instrument (VitQol).

VitQol questions	Average (SD)
1. Have you been bothered by the appearance of your skin problem?	**4.5**
2. Have you been frustrated with your skin problem?	3.9
3. Have you found it difficult to show affection because of your skin problem?	3.3
4. Has your skin problem affected your daily activities?	3.2
5. When talking to someone, did you worry about what they might think of you?	4.0
6. Were you afraid that people would criticize you?	3.9
7. Have you felt embarrassed or inhibited because of your skin?	3.9
8. Has your skin problem influenced the type of clothes you wear?	3.4
9. Has your skin problem affected your social or leisure activities?	3.5
10. Has your skin problem affected your emotional well-being?	**4.4**
11. Has your skin problem affected your overall physical health?	3.2
12. Has your skin problem influenced your personal appearance care (for example, haircut or use of cosmetics)?	3.7
13. Has your skin problem influenced your sun protection care during leisure time (e.g., limiting exposure time during peak sun hours, seeking shade, or wearing a hat, long sleeves, or pants)?	**4.8**
14. Has your skin problem affected your ability to make new friends?	2.5
15. Have you worried about the progression of your disease to new areas of your body?	**4.8**
16. Please assess how severe you feel your skin problem is.	**4.5**

Source: Elaborated by the authors.

DISCUSSION

Vitiligo is the frequent pathology worldwide when it comes to pigmentary disorders, but of unknown origin. The treatments are conservative and directed to cosmetic care, because currently there is still no curative therapy for the disease[12].

Despite the unknown causes, there is extensive research linking emotional factors with the development of the disease. It is believed that repressed or poorly resolved emotions can lead to organic responses and interfere with treatment[6,8,13].

Vitiligo is a prevalent disease in females and in the young and adult age groups[14.] A cross-sectional study conducted in Brazil with the objective of describing the clinical and epidemiological profile of patients corroborated this statistic, by describing that 72.2% of the patients analyzed were women in adulthood[15]. This scenario is worrisome, since this population presented greater QoL impairment and psychological alteration, affecting their family and society[16].

Although there is scientific evidence that vitiligo does not cause harm to physical health and is not contagious, the emotional impact and damage to individuals is incalculable[16]. A case-control study associated QoL and perceived stress in 51 individuals with vitiligo and highlighted a slight impact of the disease on QoL; however, the level of perceived stress was high, indicating that the disease increases the level of stress[17].

In this context, there is great concern among individuals regarding the increase and intensity of the spots, resulting in reduced sun exposure and often reducing their leisure activities[18]. Localized or generalized patches are associated with impact on QoL. Therefore, techniques such as camouflage are described as improving the individual's acceptance and QoL[19].

A recent study evaluated 104 individuals with vitiligo and looked at QoL and the prevalence of depression. The results corroborated those of the present study by evidencing moderate impact on QoL and a prevalence of 13.3% of people with depression. Factors influencing QoL were manifestations of new macules, active disease, lesions in exposed regions, and the black skin phototype[20].

Therefore, individual and group consultations are significant for a comprehensive approach that encompasses QoL in the management and treatment of individuals with vitiligo[21].

CONCLUSION

The vitiligo pathology interfered with the QoL of adult subjects. Factors that impacted QoL were intensified skin care in leisure activities, concern about disease progression, and the appearance of the hypochromic patches.

Further studies are recommended to evaluate health interventions to improve the QoL of individuals with vitiligo, as well as to identify the main factors that impact QoL in different regions of Brazil, in order to guide professionals in the care of this population.

It is emphasized that, because of the pandemic scenario during data collection, the composite sample was inhomogeneous.

AUTHORS' CONTRIBUTION

Substantive scientific and intellectual contributions to the study: Domingues EA; **Conception and design:** Domingues EA; **Data collection, analysis and interpretation:** Silva FS; **Article writing:** Domingues EA, Silva FS, Kaizer UAO, Fonseca JPS, Silva RS, Dzivielevski AMO; **Critical revision:** Domingues EA, Silva FS, Kaizer UAO; **Final approval:** Domingues EA, Silva FS, Kaizer UAO, Fonseca JPS, Silva RS, Dzivielevski AMO.

AVAILABILITY OF RESEARCH DATA

All data were generated or analyzed in the present study.

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