




Assessment of the quality of life of people with vitiligo: cross-sectional study

Avaliação da qualidade de vida de pessoas com vitiligo: estudo transversal

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ABSTRACT | OBJETIVO: To evaluate the impact of vitiligo on the quality of life of residents in Salvador. **METHOD:** Cross-sectional study carried out using a virtual questionnaire, developed on the Google Forms® platform. In addition to sociodemographic and clinical data, the Vitiligo-specific health-related quality of life instrument (VitiQoL) questionnaire was applied. Descriptive and inferential statistics were performed. To compare continuous non-parametric variables, the Mann Whitney and Kruskal Wallis tests were used. **RESULTS:** A total of 70 participants were gathered, with a median age of 31 years, predominantly women (70.0%), mixed race (44.3%), single (51.4%), and with higher education (54.3%). The median time since diagnosis was 10 years, and most had lesions in exposed areas (82.9%). There was a significant impact of vitiligo on quality of life (final score of 47 points), particularly concerning worry about disease progression (6.0 points), sun protection care (6.0 points), and interference with emotional well-being (5.0 points). Factors such as participation limitation, stigma, and behavior indicated a moderate to significant impact on participants' lives, with women being more affected ($p=0.001$). **CONCLUSION:** Vitiligo affects quality of life, with a greater effect among women. The emotional impact was significant, although daily activities, the ability to show affection, and to make new friends were minimally affected.

KEYWORDS: Vitiligo. Quality of Life. Psychological Stress.

RESUMO | OBJETIVO: Avaliar o impacto do vitiligo na qualidade de vida de residentes em Salvador. **MÉTODO:** Estudo transversal realizado utilizando questionário virtual, desenvolvido na plataforma Google Forms®. Além de dados sociodemográficos e clínicos, aplicou-se o questionário *Vitiligo-specific health-related quality of life instrument* (VitiQoL). Foram realizadas estatísticas descritivas e inferenciais. Para comparar variáveis contínuas não paramétricas, foram utilizados os testes *Mann Whitney* e *Kruskall Wallis*. **RESULTADOS:** Foram reunidos 70 participantes, idade mediana de 31 anos, predomínio de mulheres (70,0%), raça parda (44,3%), solteiros (51,4%), ensino superior completo (54,3%), tempo de diagnóstico de 10 anos, com lesões expostas (82,9%). Houve impacto do vitiligo na qualidade de vida (escore final 47 pontos), com destaque para a preocupação com a progressão da doença (6,0 pontos), com os cuidados com a proteção solar (6,0 pontos) e interferência no bem estar emocional (5,0 pontos). Os fatores de limitação da participação, estigma e comportamento indicaram impacto moderado a significativo na vida dos participantes, sendo as mulheres mais afetadas ($p=0,001$). **CONCLUSÃO:** O vitiligo modifica a qualidade de vida, com maior efeito entre as mulheres. O impacto emocional foi expressivo, embora as atividades diárias, a capacidade de demonstrar afeto e de fazer novos amigos tenham sido pouco afetadas.

PALAVRAS-CHAVE: Vitiligo. Qualidade de Vida. Estresse Psicológico.

1. Introduction

Vitiligo is a disorder characterized by areas of macular depigmentation, which not only causes aesthetic changes but can also trigger significant psychosocial issues, such as low self-esteem and negative impacts on quality of life.^{1,2} It is a complex disease, characterized by achromic spots, generally bilateral and symmetrical, resulting from the selective loss of melanocytes. Its pathogenesis involves an interaction of genetic components, metabolic factors related to cellular oxidative stress, melanocyte adhesion to the epithelium, and both innate and adaptive immunological mechanisms that culminate in the destruction of melanocytes.^{1,3} Although its etiology remains unknown^{1,3}, the diagnosis is clinical and can occur at any age, with approximately 25% of patients being under 10 years old and 95% of cases arising before the age of 40.³

It is estimated that vitiligo affects between 0.46% and 0.68% of the population in Brazil, with no difference between genders.⁴ Since most patients develop the disease in early adulthood, vitiligo can influence the personal, psychological, and professional development of affected individuals. Many patients experience symptoms of depression and anxiety, which can negatively impact their social life, leading to isolation.⁵

In physical terms, vitiligo causes little repercussion and may even be underdiagnosed due to its lack of symptoms and absence of threats to patient integrity.⁶ Perhaps for this reason, many doctors consider it merely an aesthetic alteration, neglecting or disregarding the profound psychological impact it causes.^{5,7} However, socially, this disease can result in serious consequences, such as social embarrassment, shame, anxiety, low self-esteem, and depression, factors that directly interfere with the patient's quality of life.⁷

Although the literature includes articles on the disease's pathophysiology and already presents evidence of the relationship between vitiligo and

depression, anxiety, and low self-esteem, particularly at the international level^{3,8,9}, studies addressing the disease's impact on the quality of life of Brazilians are still scarce. In light of this, the present study aims to assess the impact of vitiligo on the quality of life of residents of Salvador, Bahia, in addition to examining their sociodemographic profile.

2. Methods

An observational epidemiological study was conducted with residents of the city of Salvador who declared having been diagnosed with vitiligo.

Participants included individuals of both sexes, over 18 years old, residing in Salvador, Bahia, who agreed to participate in the study by signing the virtual Informed Consent Form (ICF). Questionnaires that were incompletely filled out were excluded. The sampling selection was not directed at a specific neighborhood but instead included residents from any area of the city. This approach aimed to achieve broader representation of the impact of vitiligo on quality of life without limiting the analysis to a restricted geographic area.

Participants were invited to take part in the study through the snowball method, a non-probabilistic sampling technique in which current study subjects recruit future subjects from among their acquaintances to increase the number of participants.¹⁰ The study was disseminated through specific social media profiles such as Instagram and Facebook, using accounts that support patients with vitiligo. Additionally, contact was made with leaders of vitiligo associations and support groups, who acted as focal points for spreading the study. WhatsApp message groups created by patients and vitiligo support associations were also used to share the questionnaire link. These groups were identified through contacts established via social media or through the vitiligo support associations.

For data collection, the Google Forms link was shared via WhatsApp messages as well as posts and stories on Instagram and Facebook. The form contained all the information about the study, the ICF, and the questionnaire to be answered. Responses were accepted between August 8, 2021, and September 30, 2021. The questions in the form were not mandatory, respecting the ethical principle of participant autonomy. Contact information for the researchers was provided to address any questions during and after data collection.

The Vitiligo-specific health-related quality of life instrument (VitiQoL)¹¹, validated for the Brazilian population, was used to assess the quality of life of vitiligo patients. The VitiQoL aims to evaluate the impact of vitiligo on the patient's quality of life over the past month through 16 objective questions with responses ranging from 0 to 6 points, yielding a maximum score of 90 points. Scores closer to the maximum (90 points) indicate a greater impairment of quality of life.

In addition to the VitiQoL, sociodemographic data (age, sex, race, marital status, education, family income) and clinical data (time since diagnosis and body areas affected by the disease) were collected. For the classification of body areas, exposed areas included the head, neck, arms, forearms, hands, thighs, legs, and feet, while the trunk and pelvis were categorized as non-exposed areas.

Data analysis was performed using the SPSS (Statistical Package for the Social Sciences) software. Considering descriptive statistics, categorical variables were presented through frequency distributions,

represented in absolute frequency (n) and relative frequency (%). Numerical variables were presented as medians (ME) and Interquartile Range (IQR, 25%-75%) as they displayed asymmetrical distributions according to the Kolmogorov-Smirnov test. The comparison between non-parametric continuous variables was performed using the Mann-Whitney and Kruskal-Wallis tests. Values of $p < 0.05$ were considered statistically significant.

The study adhered to all ethical guidelines for research involving human subjects and is in compliance with Resolutions 466/12 and 510/16 of the Brazilian National Health Council. Additionally, the study was approved by the Ethics Committee for Research at the Instituto Mantenedor de Ensino Superior da Bahia (CAAE n° 38869420.5.0000.5032).

3. Results

A total of 119 questionnaires were completed, of which 49 were excluded for not meeting the eligibility criteria. Thus, the final sample for this study consisted of 70 individuals who reported having vitiligo and resided in Salvador, Bahia.

The study results indicated that the median age of participants was 31 years, with a predominance of females (n=49, 70.0%), mixed race (n=31, 44.3%), single (n=36, 51.4%), having completed higher education (n=38, 54.3%), and with a family income of more than seven minimum wages (n=33, 47.1%). Clinically, the median time since diagnosis was 10.0 years, and there was a predominance of lesions in exposed areas of the body (n=58, 82.9%) (Table 1).

Table 1. Sociodemographic and clinical characteristics of individuals with vitiligo participating in the study. Salvador/BA, 2022

Characteristics	Sample (n=70)
Age in years, ME (IQR)	31.0 (24.7-49.0)
Sex, n (%)	
Female	49 (70)
Male	21 (30)
Race, n (%)	
White	29 (41.4)
Mixed	31 (44.3)
Black	10 (14.3)
Marital status, n (%)	
Single	36 (51.4)
Married	28 (40.0)
Divorced	4 (5.7)
Widowed	2 (2.9)
Education level, n (%)	
Elementary School	5 (7.1)
High School	27 (38.6)
College degree	38 (54.3)
Household income, n (%)	
1 to 3 minimum wages	15 (21.4)
3 to 5 minimum wages	11 (15.7)
5 to 7 minimum wages	11 (15.7)
> 7 minimum wages	33 (47.1)
Diagnosis time in years, ME (IQR)	10.00 (6.0-20.2)
Affected body area, n (%)	
Exposed*	58 (82.9)
Non-exposed**	12 (17.1)

Subtitle: n: absolute number; %: percentage; ME: Median; IQR: Interquartile Range; *Exposed area: head, neck, arms, forearms, hands, thighs, legs, and feet; **Non-exposed area: trunk and pelvis.

Source: the authors (2024).

When analyzing the results of the VitiQoL, it was observed that the median responses indicate a significant impact of vitiligo on the participants' quality of life across several dimensions (Table 2). The most concerning issue for respondents was the worry about the progression of the disease to new areas of the body (Q15 - median 6.0 [IQR 5.0-6.0]), followed by the influence on sun protection care during leisure time (Q13 - median 6.0 [IQR 4.0-6.0]). Additionally, the appearance of the skin condition caused considerable discomfort (Q1 - median 4.0 [IQR 2.0-5.0]) and frustration (Q2 - median 3.5 [IQR 1.7-5.0]), with a notable emotional impact (Q10 - median 5.0 [IQR 2.0-6.0]).

Table 2. Analysis of the impact of vitiligo on quality of life assessed by the VitiQoL questionnaire. Salvador/BA, 2022

VitiQoL Questions	Median	IQR
Q1 - Have you been bothered by the appearance of your skin problem?	4.00	2.0-5.0
Q2 - Have you felt frustrated because of your skin problem?	3.5	1.7-5.0
Q3 - Have you had difficulty showing affection because of your skin problem?	0	0.0-2.0
Q4 - Has your skin problem affected your daily activities?	1.0	0.0-2.0
Q5 - When talking to someone, do you worry about what they might be thinking about you?	2.0	0.0-4.0
Q6 - Have you been afraid of being criticized by others?	2.0	0.0-4.0
Q7 - Have you felt ashamed or inhibited because of your skin?	3.0	0.7-5.0
Q8 - Has your skin problem influenced the type of clothes you wear?	1.0	0.0-4.0
Q9 - Has your skin problem affected your social or leisure activities?	1.0	0.0-4.0
Q10 - Has your skin problem affected your emotional well-being?	5.0	2.0-6.0
Q11 - Has your skin problem affected your overall physical health?	2.0	0.0-3.0
Q12 - Has your skin problem influenced your personal care and grooming?	3.0	0.0-6.0
Q13 - Has your skin problem influenced your sun protection care during leisure time?	6.0	4.0-6.0
Q14 - Has your skin problem affected your ability to make new friends?	0.0	0.0-1.0
Q15 - Do you worry about the progression of your disease to new areas of your body?	6.0	5.0-6.0
Q16 - How severe do you feel your skin problem is?	3.0	2.0-4.0
Participation Limitation Factor	2.4	0.8-3.4
Stigma Factor	2.9	1.0-4.2
Behavior Factor	3.2	2.2-4.0
Total Score	47.0	25.2-61.2

Subtitle: VitiQoL: Vitiligo-specific health-related quality of life instrument; IQR: Interquartile Range; Q: Question.
Source: the authors (2024).

Regarding the questions that were least influenced, most participants did not experience difficulty in showing affection (Q3 - median 0.0 [IQR 0.0-2.0]), did not have their daily activities significantly affected (Q4 - median 1.0 [IQR 0.0-2.0]), and did not feel that their ability to make new friends was impacted (Q14 - median 0.0 [IQR 0.0-1.0]).

The "participation limitation" factor had a median of 2.4 (IQR 0.8-3.4), indicating that vitiligo caused a moderate limitation in the social and leisure activities of the individuals. The "stigma" factor showed a median of 2.9 (IQR 1.0-4.2), suggesting that participants felt a moderate level of stigmatization due to their skin condition. The "behavior" factor had the highest median among the three (3.2 [IQR 2.2-4.0]), indicating that vitiligo significantly influenced behaviors related to personal care and sun protection. The total VitiQoL score, with a median of 47.0 (IQR 25.2-61.2), reflects a moderate overall impact of vitiligo on the participants' quality of life, considering that scores closer to the maximum value indicate a greater impairment of quality of life.

When analyzing the VitiQoL according to the sociodemographic and clinical profile of the participants (Table 3), it was observed that females experienced a greater impact on quality of life compared to males ($p < 0.01$). No statistically significant differences were observed between age groups, races, marital status, education level, family income, or affected body areas.

Table 3. Impact of vitiligo on quality of life considering the sociodemographic and clinical characteristics of the study participants. Salvador/BA, 2022

Characteristics	VitiQoL. ME (IQR)	p-value
Age group		0.16*
Youth (up to 19 years old)	62.0 (60.0-62.0)	
Adult (20 to 59 years old)	44.0 (23.0-61.0)	
Elderly (60 years old and above)	46.5 (18.2-63.0)	
Sex		<0.01^{&}
Female	52.0 (30.5-64.5)	
Male	30.0 (11.0-44.5)	
Race		0.63*
White	51.0 (27.5-61.5)	
Mixed	39.0 (23.0-60.0)	
Black	54.0 (12.2-67.0)	
Marital status		0.14*
Single	53.5 (24.0-66.7)	
Married	34.0 (20.7-51.7)	
Divorced	40.0 (10.0-63.2)	
Widowed	46.5 (40.0-46.5)	
Education level		0.32*
Elementary School	53.0 (33.5-65.0)	
High School	53.0 (22.0-63.0)	
College degree	37.5 (23.2-58.0)	
Household income		0.54*
1 to 3 minimum wages	53.0 (18.0-63.0)	
3 to 5 minimum wages	39.0 (10.0-50.0)	
5 to 7 minimum wages	49.0 (27.0-57.0)	
> 7 minimum wages	51.0 (29.0-63.0)	
Affected body area		0.12^{&}
Exposed	36.5 (12.5-53.2)	
Non-exposed	50.0 (27.0-63.2)	

VitiQoL: Vitiligo-specific health-related quality of life instrument; ME: Median; IQR: Interquartile Range; *: Kruskal-Wallis test; &: Mann-Whitney test.
Source: the authors (2024).

In evaluating the severity of the impact of vitiligo on the quality of life of participants based on question 16 of the VitiQoL, higher scores were observed for women compared to men, with this difference being statistically significant ($p < 0.01$). No statistically significant differences were observed in the score among age groups ($p = 0.09$), duration of diagnosis ($p = 0.34$), presence of exposed and non-exposed lesions ($p = 0.198$), races ($p = 0.75$), education level ($p = 0.36$), and marital status ($p = 0.07$).

4. Discussion

The present study demonstrated that vitiligo impacts the quality of life of individuals residing in Salvador, Bahia, with this effect being more pronounced among women. Furthermore, the study revealed a predominant profile characterized by women, young people (up to 19 years old), of mixed race, single, with higher education, and a family income above seven minimum wages.

According to the data obtained in this study, there was a higher prevalence among women, which may reflect not only biological differences but also patterns of seeking medical care more frequently than men.¹² Similarly, the prevalence among young people aligns with the evolutionary profile of the disease, which often manifests before the age of 30 in 80% of cases.¹³

Regarding race, the prevalence of individuals of brown (or mixed) race contrasts with a previous study¹⁴, highlighting Brazil's ethnic diversity and its implications for the experience of vitiligo. Although vitiligo affects individuals of all races, in patients with black skin, the impact on quality of life is more significant due to the striking contrast between the white spots and the black skin tone, which tends to attract more social attention.¹⁴

A higher prevalence of individuals with higher education was demonstrated, corroborating the study by Oliveira¹⁵, which found 48.3%, and by Chen and collaborators¹⁶, which found 49.4% of their respective samples. However, the studies by Boza and collaborators¹⁷ and Bassiouny and collaborators¹⁸ showed that the majority of participants had completed high school or secondary education, evidencing 37.6% and 43% of their samples, respectively. In this context, it is known that education plays an important role as a social determinant, potentially affecting an individual's life indirectly and, consequently, impacting their quality of life.^{15,18}

The analysis of the VitiQoL responses revealed a statistically inferior quality of life among women, corroborating previous studies.¹⁶⁻¹⁸ The pressure for an ideal aesthetic standard is particularly more pronounced in females, where, many times, an unattainable concept of beauty is sought.^{16,19} This scenario makes it increasingly difficult to cope in a healthy manner with other characteristics that do not fit this societal ideal of beauty.¹⁹ These findings emphasize the need to consider gender aspects in the approach to vitiligo.

The results of the VitiQoL revealed that the fear of disease progression and the concern for sun protection were the most impactful factors on the quality of life of individuals with vitiligo. The worry about the progression of vitiligo to new areas of the body may be related to the unpredictable course of the disease and the lack of a definitive and fully effective treatment, causing discomfort for those affected by this depigmentation disorder.¹³ Additionally, individuals with vitiligo are at a higher risk of developing skin cancer, which creates the need for greater protection from sun exposure.²⁰ The discomfort with appearance may be explained by the damage this disease causes to individuals' self-esteem, which can even lead to severe social, sexual, and professional limitations.^{21,22}

Moreover, the present study demonstrated that the questions least impacted by vitiligo were associated with the demonstration of affection, daily activities, and difficulties in making new friends. These data may be explained by the influence of various factors on the quality of life of individuals with vitiligo, including personality traits, sociodemographic characteristics,

and the very nature of the disease, such as its duration and extent.^{20,22} These elements play a crucial role in how patients cope with and adapt to the psychological impact of vitiligo.

Vitiligo can affect people's lives in various ways, sometimes being psychologically devastating.¹⁴ Despite this, the present study observed a significant difference (total median of 47 points) compared to the study by Oliveira¹⁵ (total mean of 25 points) and the study by Boza and collaborators¹⁷ (total median of 37 points). This finding may be attributed to the favorable socioeconomic profile of the analyzed sample. These characteristics may contribute to patients having greater access to dermatologists and treatments that reduce the progression of affected areas.¹⁵ However, it is important to recognize that populations with lower incomes, low education levels, and limited access to specialized healthcare services may face additional challenges in managing vitiligo, highlighting the need for more inclusive and accessible public policies.

Given this reality, the recent National Policy for the Prevention, Treatment, and Control of Chronic Skin Diseases²³ represents a significant advancement in addressing chronic skin diseases, including vitiligo. However, its implementation requires a coordinated effort to ensure that all patients, regardless of their socioeconomic condition, have adequate access to quality dermatological care.

This study, although presenting relevant data on the impact of vitiligo on quality of life, has some limitations to be considered. The main limitation is the limited sample size, which is due to the method of participant recruitment. Additionally, the snowball sampling method may introduce selection bias due to the tendency of recruited participants to share similar characteristics or belong to the same social groups, decreasing the sample variability. Another limitation is the cross-sectional nature of the study, which prevents the determination of causal relationships between the studied variables. Nevertheless, despite these limitations, the present investigation provides valuable insights that may contribute to future studies aimed at providing educational interventions and observing their impact on the quality of life of people with vitiligo.

5. Conclusion

This study demonstrated that vitiligo impacts the quality of life of individuals residing in Salvador, Bahia, with a greater effect among women. Despite the predominance of young, mixed-race, single participants with a high level of education and elevated family income, concerns about disease progression and the influence on sun protection care were the most affected aspects across all profiles. The emotional impact was significant, although daily activities, the ability to demonstrate affection, and make new friends were less affected.

The results suggest that women may experience a greater impact on their quality of life compared to men, indicating the need to consider emotional support interventions and strategies to mitigate the stigma associated with vitiligo.

Contributions of the authors

The authors declared that they made substantial contributions to the work in terms of the conception or design of the research; the acquisition, analysis, or interpretation of data for the work; and the writing or critical revision of relevant intellectual content. All authors approved the final version to be published and agreed to take public responsibility for all aspects of the study.

Conflicts of interest

No financial, legal, or political conflict involving third parties (government, companies, and private foundations, etc.) was declared for any aspect of the submitted work (including, but not limited to, grants and funding, participation in advisory boards, study design, manuscript preparation, statistical analysis, etc.).

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