U.PORTO

MESTRADO INTEGRADO EM MEDICINA

Exploring the Impact of Vitiligo on Patients' Quality of Life

Alice Ferreira da Costa

M

2025

Exploring the Impact of Vitiligo on Patients' Quality of Life

Artigo de Revisão Bibliográfica

Dissertação de candidatura ao grau de Mestre em Medicina, submetida ao Instituto de Ciências Biomédicas Abel Salazar - Universidade do Porto

Estudante

Alice Ferreira da Costa

Estudante do 6º ano de Mestrado Integrado em Medicina

Instituto de Ciências Biomédicas Abel Salazar, Universidade do Porto

Endereço eletrónico: up201906540@up.pt

Orientador

Professor Doutor Tiago da Costa Ferreira Torres

Assistente Graduado do Serviço de Dermatovenereologia do Centro Hospitalar Universitário de Santo António

Professor Associado do Instituto de Ciências Biomédicas Abel Salazar, Universidade do Porto



Coorientador

Dr. César Jesus Silva Ferreira

Interno de formação específica de Dermatovenereologia da Unidade Local de Saúde do Santo António

Colaborador externo



Junho 2025

Declaração de Integridade Científica

Eu, Alice Ferreira da Costa, número mecanográfico 201906540, estudante do 6º ano do Mestrado Integrado em Medicina do Instituto de Ciências Biomédicas Abel Salazar, Universidade do Porto, declaro que a presente dissertação foi elaborada com integridade científica. Confirmo que não recorri à prática de plágio ou à utilização indevida de material de terceiros. Toda a informação proveniente de publicações anteriores, pertencente a outros autores, foi devidamente referenciada no texto, e citada na bibliografia.

Porto, junho de 2025.



(Alice Ferreira Costa)

Dedication

To my mother, for her unconditional and unwavering support, and for always believing in me through every stage of this journey.

Acknowledgments

To Professor Dr. Tiago Torres, who readily agreed to supervise this dissertation and suggested its topic. My sincere gratitude for his guidance and availability, both of which were essential to the development of this work. To my co-supervisor, Dr. César Ferreira, for sharing his knowledge.

To my family, for their unconditional support throughout my entire academic journey.

Resumo

Vitiligo é uma dermatose inflamatória crónica caracterizada por despigmentação cutânea, resultante da perda de melanócitos. Apresenta uma prevalência global estimada entre 0,5% e 2%, afetando igualmente ambos os sexos e todas as raças. Embora possa surgir em qualquer idade, o início é mais frequente na infância ou no início da idade adulta. A sua patogénese é multifatorial, envolvendo suscetibilidade genética, mecanismos autoimunes e desregulação imunitária. As lesões tendem a surgir inicialmente em zonas fotoexpostas, como o rosto e as mãos, progredindo, geralmente de forma lenta, em até 90% dos doentes. Apesar das diversas modalidades terapêuticas disponíveis, que visam estabilizar a doença e promover a repigmentação, os resultados permanecem inconsistentes e com benefícios limitados.

Embora assintomático e muitas vezes considerado uma doença meramente estética, o vitiligo tem demonstrado afetar profundamente a qualidade de vida dos doentes, interferindo na sua autoimagem, bem-estar psicológico e funcionamento social. A cronicidade da doença, a eficácia limitada dos tratamentos, e a presença frequente de comorbilidades contribuem ainda mais para o seu impacto psicológico. Nos últimos anos, a crescente consciencialização destes efeitos tem vindo a reforçar a importância da avaliação da qualidade de vida no contexto da abordagem terapêutica do vitiligo, sublinhando a necessidade de uma abordagem holística centrada na pessoa.

A presente revisão bibliográfica tem como objetivo identificar e analisar o impacto do vitiligo na qualidade de vida dos doentes, através da análise da literatura científica disponível. Pretende ainda explorar os principais fatores que influenciam esse impacto, bem como apresentar as diversas metodologias utilizadas na avaliação da qualidade de vida em indivíduos com vitiligo.

Palavras-chave: Vitiligo, Quality of Life, Psychosocial Impact.

Abstract

Vitiligo is a chronic inflammatory dermatosis characterized by skin depigmentation due to the loss of melanocytes. It has an estimated global prevalence of 0.5-2%, affecting all sexes and races equally. Although it can occur at any age, onset is most common in childhood or early adulthood. Its multifactorial pathogenesis involves genetic susceptibility, autoimmune mechanisms and immune dysregulation. Typical lesion onset happens in sun-exposed areas, such as the face and hands, and progression, often slow, occurs in up to 90% of patients. Despite various treatment modalities aiming to stabilize the disease and promote repigmentation, outcomes remain inconsistent and with limited benefit.

Although asymptomatic and often regarded as a mere cosmetic condition, vitiligo has been shown to profoundly impair patients' quality of life, affecting their self-image, psychological well-being, and social functioning. The chronicity of the disease, limited treatment efficacy, and frequent comorbidities further contribute to its psychological burden. In recent years, growing awareness of these effects has highlighted the importance of assessing quality of life in the management of vitiligo, emphasizing a need for a holistic approach to patient care.

This literature review aims to identify and analyze the impact of vitiligo on patients' quality of life by examining the available scientific literature. It also seeks to explore the main factors influencing this impact, as well as to demonstrate the various methodologies used to evaluate quality of life in individuals with vitiligo.

Keywords: Vitiligo, Quality of Life, Psychosocial Impact.

List of abbreviations

BSA: Body Surface Area

CDLQI: Children's Dermatology Life Quality Index

DLQI: Dermatology Life Quality Index

EADV: European Academy of Dermatology and Venereology

HRQoL: Health-related quality of life

NS: Non-segmental

QoL: Quality of life

SF-36: Short Form-36 Health Survey

UVB: Ultraviolet B

VIPs: Vitiligo Impact Patient scale

VIS: Vitiligo Impact Scale

VitiQoL: Vitiligo Quality of Life

VLQI: Vitiligo Life Quality Index

WHO: World Health Organization

Index

Introduction 1
Methods 2
Quality of life in Vitiligo 3
  Defining quality of life 3
  Quality of life assessment 4
Disease-related factors 6
Influence of therapeutic interventions 8
Autoimmune comorbidities 9
Influence of demographic factors 10
  Gender 10
  Age 10
  Skin phototype 11
Economic burden 12
Perceptions of vitiligo 14
Psychosocial burden 15
  Stigma and self-esteem 15
  Depression and anxiety 16
  Psychological burden in Childhood 17
  Sexual dysfunction and marital relationships 17
Strategies to reduce distress 19
Conclusion 20
References 21

Introduction

Vitiligo is an acquired chronic inflammatory dermatosis characterized by the selective destruction of functional melanocytes in the epidermis that leads to depigmentation of the affected skin area. The resulting characteristic lesions are chalky-white macules and patches, with distinct margins, non-scaly, and of variable size. Both sexes are equally affected. Although it can happen at any age, lesion onset usually occurs in young people, with 25% of patients developing the disease before the age of 10 and almost 70% before the 4th decade of life. Globally, the estimated prevalence of vitiligo ranges from 0.5 to 2%, affecting people with different skin types and races in equal manner [1-4]. As a multifactorial disorder, vitiligo is influenced by both environmental and genetic factors, with multiple mechanisms having been proposed. These include genetic predisposition, autoimmune responses, oxidative stress and melanocyte intrinsic abnormalities, with both innate and adaptative immunity being involved. [1, 5, 6]

"Vitiligo" is now proposed as a consensus term to designate all forms of non-segmental (NS) vitiligo, which includes the generalized, acrofacial, universal, mucosal, mixed and rare variants [7]. The most common form, generalized vitiligo, is characterized by bilateral, often symmetrical, depigmented macules occurring in random parts of the skin. Segmental vitiligo refers to a unilateral segmental distribution of the lesions, typically associated with a rapid spreading of a few weeks or months [1, 8]. The diagnosis of vitiligo is generally clinical, especially when the presentation is classic. Vitiligo usually begins in sun-exposed areas, such as the face and the dorsal surface of the hands, and emotional stress and skin trauma, like repeated friction, may precede onset [8, 9]. Progression occurs in almost 90% of patients, usually slowly, either by expansion of existing lesions or the appearance of new ones. [1, 2, 6]

Determining disease stability is crucial for guiding treatment decisions, but the concept of disease stability can be interpreted in different ways. While clinical scoring methods, such as the Vitiligo European Task Force assessment, categorize disease into progressive, regressive, or stable stages, individual lesions may evolve differently. Therefore, "overall" stability is an unreliable assessment. Careful analysis of individual lesions combined with patient self-reporting and serial digital imaging is thus a more ideal way of assessing stability. [7, 10]

Currently, there is no curative treatment available for vitiligo. The main treatment goals are to halt and prevent disease progression and to stimulate repigmentation. So far, treatment outcomes remain inconsistent, and many patients experience limited benefit. To address these challenges, several new therapies are being developed and investigated [11, 12]. First-line therapy usually consists of phototherapy, especially narrow-band UVB, topical or systemic corticosteroids, and topical calcineurin inhibitors. While many patients are adequately treated with these therapies, a subset of vitiligo patients fail to respond to treatment. Surgical therapies, such as skin grafts, are suitable for therapy-resistant stable vitiligo. Another option available is depigmentation therapy, although it

should only be considered in extremely rare cases and after exploitation of all the other options, due to its irreversible nature. [13]

Patients with vitiligo may experience less symptomatic impairment in comparison to other skin conditions like atopic dermatitis and psoriasis, as it is not typically associated with pruritus or other acute symptoms. This leads to vitiligo often being dismissed as a cosmetic disorder and overlooked by clinicians. However, the impact these white patches have on self-image and psychosocial well-being is profound and extends to various facets of life, from social interactions to employment opportunities. Emotional distress, social stigma, and psychological conditions, such as anxiety and depression, are frequently reported among these individuals and often overshadowed. Higher levels of psychosocial burden may also be contributed by the chronic nature of vitiligo, the absence of effective treatment and the presence of other comorbidities. This combination of emotional and social challenges underscores the importance of addressing vitiligo's impact on quality of life comprehensively. [4, 14, 15]

In recent years, there has been a growing recognition of the importance of assessing quality of life in the management of vitiligo, reflecting a more holistic approach to patient care. Thus, it is essential to comprehend the multifactorial impact of vitiligo on quality of life, influenced by clinical, demographic, and sociocultural factors, and how to assess it. [4, 16]

The aim of this literature is to identify and analyze the existing evidence regarding the psychological, social, and economic impact of vitiligo has on the patients' quality of life, including exploring the main factors associated with this burden.

Methods

Literature research was conducted in the PubMed and ScienceDirect databases to identify relevant studies on the impact of vitiligo on quality of life, published between 2010 and 2024 limited to the English language. The search terms included the following keywords, alone or in combination: "vitiligo", "quality of life", "psychosocial impact". Bibliographic references of the articles resulting from the research were consulted, when deemed relevant, including both original and review articles published from 1991 to 2024. Eligible publications included observational studies, narrative reviews, systematic reviews, clinical studies and meta-analyses, from various countries.

Quality of life in Vitiligo

Defining quality of life

Over the past decades, chronic diseases have become increasingly prevalent, largely due to advancements in medical technology, improved public health measures and better management of infectious diseases, all of which have contributed to increased life expectancy. The negative impact of these conditions on overall well-being has led patients to seek diagnosis and treatment to improve multiple aspects of their life, from their psychological health to social functioning and professional life [14, 17]. With the growing realization that patient well-being is a crucial consideration in treatment, beyond merely measuring mortality rates, the concept of quality of life (QoL) has emerged as a central focus in healthcare. [18]

QoL is a complex and multifaceted concept that can be examined at different levels, from societal well-being to specific individual circumstances. It encompasses a spectrum of human experiences, conditions, perceptions and domains of thought related to an individual or community. Its definition and interpretation have evolved to reflect this diversity. [17, 19]

The World Health Organization (WHO) defines health not simply as the absence of disease but as a state of complete physical, mental and social well-being. On the other hand, the definition of QoL is more complex, with the WHO describing it as "an individual's perception of their position in life in the context of the culture and value system in which they live and in relation to their goals, expectations and standards and concerns". It is a subjective assessment of a person's well-being that includes elements such as physical health, psychological state, social relationships and employment status [15]. Although many definitions emphasize individual perceptions, some researchers argue that objective indicators should also be considered [18, 19]. Another QoL definition is of a multidimensional construct encompassing physical, psychological, functional and social well-being. Physical well-being refers to the ability to perform daily activities without significant pain or physical limitations. Psychological well-being comprises emotional and mental health, including levels of stress, anxiety, and depression. Social encompasses relationships with family, friends, and the ability to participate in social activities. Finally, functional well-being alludes to the ability to maintain autonomy and effectively perform personal and professional roles. [20]

Another important characteristic suggested by some authors is that QoL has the same components for all people. Naturally, the individual value placed on each component will vary significantly due to cultural, socioeconomic and generational differences. However, the crucial idea is that there is a recognizable set of fundamental elements of life quality that are universally shared. This implies it is possible to create generic instruments for QoL measurement that can be employed with any group and let us compare between groups and individuals. [21]

The use of the terms QoL and health status preceded the use of Health-related quality of life (HRQoL). HRQoL is a multidimensional concept comprising three key domains: physical, psychological, and social functioning, all of which can be affected by illness and/or treatment.

Physical functioning pertains to the capacity to carry out daily activities, as well as the physical symptoms caused by the disease or its treatment. Psychological functioning refers to the overall emotional state, spanning from a positive sense of well-being to significant distress, and may also include cognitive abilities. Social functioning pertains to the quantity and quality of social relationships and interactions and societal integration [17, 22]. An important aspect of HRQoL is how patients evaluate their current level of functioning and their satisfaction with it, compared to their perceived ideal state. Assessing a patient's health status involves personal experiences shaped by the progression of chronic diseases over time, even in the absence of specific treatment. Therefore, estimating the relative impact of chronic diseases on HRQoL is essential and should be actively integrated into clinical decision-making to improve not only treatment outcomes but also overall QoL. [18, 20]

Quality of life assessment

Over time, several tools have been developed to assess the impact of vitiligo on QoL. Currently, the success of medical interventions is evaluated from the patient's perspective, rather than relying solely on traditional methods of QoL assessment. This shift is particularly important in dermatology, as it allows for a more effective understanding of the impact of skin conditions. Currently, there are several instruments, both dermatology-specific and vitiligo-specific, that assess QoL and other psychosocial aspects in these patients. These instruments can be divided into three categories: generic, disease-specific, and dermatology-specific. [23]

Generic HRQoL instruments, like SF-36, allow for the comparison of QoL between individuals with vitiligo and those who are either healthy or have non-dermatologic diseases. However, they present significant limitations, such as low sensitivity to differences between treatments and low specificity in distinguishing individuals with the same disease. On the other hand, dermatology-specific and vitiligo-specific instruments offer greater sensitivity in both clinical and non-clinical changes related to the condition. [23]

The Dermatology Life Quality Index (DLQI) was developed in 1994 and was the first dermatology-specific QoL assessment tool. It is a questionnaire designed for patients over 16 years of age and covers six dimensions of HQoL: symptoms, feelings, daily activities, leisure activities, work and school, personal relationships and treatment. The scores range from 0 to 30, with scores greater than 10 indicating a very large effect on a patient's life. DLQI enables the comparison of QoL among different dermatologic diseases and has been recently recommended by the European Academy of Dermatology and Venereology (EADV) as the preferred instrument for evaluating QoL in vitiligo patients. [23-25]

It should be noted that vitiligo typically isn't associated with physical symptoms like pruritus, burning or pain. Instead, its effect on QoL is more related to psychosocial impairment. This may result in lower scores when utilizing dermatology-specific instruments, potentially underestimating

the impact of vitiligo in comparison to other dermatological conditions [23, 25, 26]. Therefore, a vitiligo-specific instrument with less emphasis on physical symptoms and more emphasis on the psychosocial and emotional burden is essential to measure HRQoL and help guide clinical management [27]. Examples of these tools include the Vitiligo Quality of Life (VitiQoL), Vitiligo Impact Scale (VIS), Vitiligo Life Quality Index (VLQI) and Vitiligo Impact Patient scale (VIPs). [23]

The VitiQoL questionnaire consists of 16 items divided into 3 domains: participation limitation, stigma and behavior [23, 28]. VIS was developed and tested in India, within a culture with great stigmatizing issues concerning vitiligo, so the tool may perform differently in other communities [23]. VLQI has a 1-week recall period which makes it possible to detect changes after short periods of time, such as following treatment. VIPs was the first specific assessment tool related to the burden of vitiligo and has different versions for patients with 'fair skin' (Fitzpatrick skin phototype I to III) and 'dark skin' (Fitzpatrick skin phototype IV to VI). [23, 29]

Since vitiligo usually begins in childhood or young adulthood, it is essential to evaluate the repercussions in HRQoL in the pediatric population. The most widely used questionnaire recommended by the EADV is the Children's Dermatology Life Quality Index (CDLQI), which is a dermatology-specific questionnaire that can be used on patients aged between 4 and 16 years. [23, 30]

In both clinical practice and research, selecting the most appropriate instrument to assess QoL in patients with vitiligo remains a challenging and often non-consensual task. Despite important efforts to develop vitiligo-specific HRQoL instruments, currently none of the existing instruments have been fully validated and DLQI remains the most used in studies. There is a strong need for a valid vitiligo-specific instrument capable of evaluating the burden of vitiligo that can be applied across both genders, regardless of age group or ethnicity. [23]

Disease-related factors

The chronic and unpredictable course of vitiligo, along with the absence of universally effective treatment, can leave patients feeling powerless and significantly impair their QoL. Many studies have sought to establish a correlation between the disease's characteristics, such as extension and visibility of lesions, and their impact on QoL. [16]

Silverberg and Silverberg showed that vitiligo lesions, no matter the area affected, were associated with significantly increased DLQI scores. Their distribution, though, was associated with impairment in different aspects of DLQI. Lesions located on visible sites of the body such as the face, arms, hands, legs and feet were significantly associated with being self-conscious about vitiligo [31]. Facial involvement was the main driver of patient-perceived vitiligo severity while lesions on the genital area and chest were significantly associated with sexual dysfunction [31, 32]. This concurs with the findings of other studies which found a significantly reduced QoL in patients with visible lesions (acrofacial and neck) and/or lesions in sensitive areas (anogenital) [4, 33-35]. These lesions can be particularly distressing, often leading to embarrassment, frustration, disappointment and even stigmatization. [36]

In addition to visibility, the extent of vitiligo has also been cited by patients as a significant factor contributing to perceived disease severity and a greater QoL impairment [33, 35]. Most studies show a reduced QoL in patients with a greater extent of affected body surface area (BSA) (most often >25%) or with lesions on several areas [3, 4]. Rosmarin et al. reported that patients with >5% BSA affected presented higher VitiQoL scores and greater impairment in the ability to perform daily activities. Consistent with this, a French study showed that >5% BSA and higher extent in visible parts led to higher QoL impairment while Silverberg and Silverberg associated it with >25% BSA [31, 35]. Another study in India assessing the relationship between disease severity and QoL also associated greater BSA affected with higher VIS-22 scores [37]. Moreover, NS vitiligo has also been associated with increased burden, in comparison to segmental vitiligo [16]. Overall, these findings suggest that patients with lesions more difficult to conceal, whether due to extent or location, have poorer QoL. They are often self-conscious and feel more anxiety, which can influence their clothing choices, social life, participation in sports or leisure activities, and even career opportunities. Also, extensive vitiligo may diminish a patient's hope of restoring pigmentation. [31, 33]

Longer duration of vitiligo has also been associated with a negative impact on people's QoL, probably due to the progression of the disease [26, 34, 38]. Lower QoL in long-standing vitiligo is likely because of the disease's chronic, relapsing nature or treatment non-compliance [37]. Patients with vitiligo for less than 5 years or between 15–20 years reported better QoL, probably reflecting early optimism for successful treatment or long-term adaptation to the condition [26]. It should also be noted that active vitiligo cases have shown significant decline in DLQI compared to stable cases, highlighting the importance of disease stabilization, as patients often feel distressed by new lesions even when repigmentation is occurring elsewhere. [34]

Patients have also reported skin symptoms, such as itching, contributing to greater disease burden. Discussed potential mechanisms for such symptoms include inflammation, higher sensitivity, and symptoms secondary to comorbid autoimmune disease or skin pathology. [31]

Another characteristic of vitiligo that might impact people's lives is sun-sensitivity. Given the reduction of photoprotective eumelanin, depigmented skin is more sensitive to UV radiation and strict application of highly potent broad-spectrum sunscreens is recommended. Avoiding activities that require sun exposure, like swimming, has been mentioned as a concern, not only due to lesions being more obvious in the summer but also because of fears of sunburn and a higher risk of skin cancer. Due to this added concern, patients have reported difficulty in maintaining adequate sun protection and having to adapt their lifestyles accordingly, thereby contributing to the overall burden imposed by vitiligo. [13, 32, 39]

Influence of therapeutic interventions

Treatment has generally been shown to lessen the impact of vitiligo on QoL in studies. In a recent study, 94% of patients indicated the need for new and improved treatments and half of the patients were not satisfied with their current treatment and found it ineffective. Even patients who were satisfied with their current therapy felt that new treatments were needed [11]. Findings from a US survey indicate that vitiligo burden is high even among patients with limited disease extent, likely due to the lack of effective treatments. Patients reported repigmentation, shrinkage of lesions (especially in visible areas), and prevention of the spread of vitiligo as treatment goals. This suggests that the impact of current interventions remains limited and requires improvement. [40]

The slow process of repigmentation together with psychosocial stress and previous repigmentation failure can affect long-term adherence to treatment. The long time needed to obtain satisfactory results also adds to the burden [4]. Apart from the type of vitiligo, therapy modality and duration, the location of the lesions is also a major prognostic factor. Facial and neck lesions are more responsive to phototherapy, while hands and feet hardly respond to any therapy [13]. It is also important to note that patient satisfaction is associated with near-complete repigmentation, as shown in a study where patients considered ≥ 80% repigmentation as successful. On the other hand, patients with facial vitiligo consider improvement in facial lesions more important, with ≥ 50% facial repigmentation needed to be considered meaningful [32]. The limited long-term success of current management strategies is also a barrier to the treatment of vitiligo. Dissatisfaction rates are high among both dermatologists and their patients, mostly due to relapse, as depigmentation recurs in around 40% of cases after intervention. [40]

Depigmentation, a more radical treatment option, has been reported by patients to lessen QoL impairment, particularly when attending social events. Although this option appears to be associated with high treatment satisfaction, discussion about the patient's goals and counseling are crucial. [41]

Another obstacle to improving QoL is the number of patients not receiving treatment. Findings from a French study indicate that most patients with vitiligo (84%) did not receive any prescribed treatment. Moreover, results showed that 65% of patients were informed that their vitiligo could not be treated. This highlights the need for additional education concerning treatment options and expected outcomes for both physicians and patients. [35]

On this note, it is essential to empower patients to take an active role in their treatment decisions, while also setting realistic expectations, especially since achieving repigmentation can be difficult and QoL improvements may be minimal. Also, although physicians may feel it is necessary to treat vitiligo, patients may feel different. Some vitiligo patients may feel vitiligo makes them unique and refuse treatment. Understanding how patients feel toward their vitiligo is thus essential, as their perspective helps guide patient-centered treatment. [4, 41]

Autoimmune comorbidities

Nowadays, vitiligo is recognized as more than just a skin disease, with mounting evidence linking it to a range of systemic disorders, including autoimmune, metabolic, dermatological and psychological disorders. [5, 42]

As previously mentioned, the autoimmune etiopathogenesis of vitiligo is one of the most widely supported theories. The detection of autoantibodies against melanocytes in affected individuals, along with the higher prevalence of concomitant autoimmune diseases, reported in 10–15% of patients with vitiligo compared to 1–2% of the general population, strongly supports this hypothesis [42]. The most common autoimmune condition reported by vitiligo patients is thyroid disease, particularly autoimmune thyroid disease [43, 44]. Other reported autoimmune comorbidities include rheumatoid arthritis, Addison's disease, inflammatory bowel disease, systemic lupus erythematosus, type 1 diabetes mellitus, alopecia areata, psoriasis, dermatomyositis, and scleroderma [42, 43]. Furthermore, patients with at least one autoimmune comorbidity tend to exhibit more extensive vitiligo, involving a larger BSA, a factor that appears to be associated with greater impairment in QoL, as previously stated. [45]

As several of these diseases contribute to the deterioration of patients' QoL, doctors need to be well-informed about them so they can help prevent and manage these additional health conditions.

Influence of demographic factors

Gender

Findings about gender differences in terms of QoL of vitiligo have generally found a more significant impact on women's QoL [4, 34, 46, 47]. Some studies, though, have found no relation between gender and QoL, possibly due to cultural differences where both male and female patients might be equally concerned with their looks emphasizing the psychological burden of chronic disfiguring disorders regardless of gender. [34, 37]

The relatively poor QoL observed in female vitiligo patients was to be expected, as women worldwide often face greater societal pressure regarding appearance. Aesthetic concerns tend to carry more weight for women, leading to a more emotional burden, with anxiety and depression, and a significant impact on self-esteem. Visible lesions further intensify this pressure, as women are more likely to experience social coercion and feel compelled to conceal their patches with clothing or cosmetic camouflage [26, 37, 46]. This can result in them avoiding social interactions, distancing themselves from family, experiencing sexual inhibition and even having work-related difficulties. The discrepancy between genders in terms of participation limitation may be attributed to the increased aesthetic pressure placed on women, which restricts their ability to engage in daily and leisure activities as freely as men, partly due to persistent myths surrounding the disease, especially in certain cultures. [37]

The difference reported between men and women could also be because it is more distressing and feels more shameful for men to reveal and discuss body image concerns. [48]

Age

The relationship between age and QoL has also been explored in multiple studies, with younger patients (< 30 years old) often reporting lower QoL [4, 26, 34, 47, 49]. One study showed that 20–29-year-old patients experienced the worst life quality, while others found a bigger QoL impairment in the age groups of 18-30 years and 13-18 years [26, 34, 50]. It makes sense that young patients with vitiligo show higher impairment in QoL and have aggravated psychological symptoms, since this is the age group with more concerns about self-appearance, especially nowadays with beauty standards dictated by social media. Young individuals with disfiguring conditions might have unmet needs for equal consideration, respect, and inclusion in social, emotional, and professional relationships [26, 50]. Meanwhile, the older population may have a better adaptation to vitiligo due to age, social stabilization or development of coping mechanisms, leading to improved emotional resilience [47]. On the other hand, Radtke et al. and Ingordo et al. did not find any statistical correlation between age and DLQI scores [38, 51]. This could because older age may be related to long-standing disease, greater extent of affected area, and even failure of treatment or relapse, which can lead to fatigue, frustration, and chronic emotional burden, resulting in reduced QoL.

Skin phototype

Darker skin phototypes have been associated with greater QoL impairment. It has been postulated that dark-skinned people attract more unwanted attention due to the contrast between vitiligo lesions and the darker skin resulting in disfiguration which may be emotionally disturbing and upsetting [46, 47]. DLQI scores for vitiligo have shown apparent geographical differences with higher mean scores in Turkish, Arabian, Egyptian, and Indian studies. Lower scores were found in an Italian study, likely due to vitiligo being less noticeable on fairer skin, more common in Europe, and the cultural differences [34, 36]. In a study about cosmetic camouflage in vitiligo, skin phototype had a significant effect on DLQI score, decreasing significantly in skin type III compared with skin type IV and V, suggesting that efficient concealment of lesions is more difficult in darker skin [34]. Worries linked to higher burden have also been reported to be different between the two groups. Patients with dark skin expressed greater concern about repercussions on their appearance while fair-skinned patients were more worried about skin cancer occurrence. The latter fear contrasts with research indicating that vitiligo is linked to a reduced risk of melanoma and nonmelanoma skin cancer, highlighting the need for better patient education by physicians. [52]

However, some studies reported no significant differences between patients with fairer and darker skin. Although patients with different skin phototypes may cope with vitiligo differently, they are all equally affected by vitiligo. [52, 53]

Economic burden

Another approach to assessing the impact of vitiligo includes evaluating its economic burden. Willingness to pay (WTP) is often used in studies to estimate the monetary value of health benefit and patient preference by asking people how much they are willing to spend for treatment to improve or heal their condition. [25, 38]

A study comparing the WTP and DLQI scores between vitiligo and other dermatologic conditions reported that vitiligo had the highest median WTP for disease cure but the lowest DLQI scores. The discrepancy between the WTP and DLQI scores could reflect the downside of the DLQI questionnaire when used in pigmentary disorders with limited symptoms [25, 54]. Nevertheless, the marked reduction in overall QoL combined with a high WTP underscores the considerable burden associated with vitiligo [4]. A positive correlation between DLQI and WTP has been demonstrated, making it clear that individuals experiencing greater QoL impairment are more willing to invest in treatment options. Conversely, those less affected tend to exhibit lower WTP.[38]

Vitiligo patients incur both healthcare expenses, stemming from the treatment of their skin condition and comorbidities, and non-healthcare costs, associated with non-drug products and indirect social costs. [55]

The costs of vitiligo treatment include all direct medical expenses, including therapies, examinations, laboratory tests, and supplements. An American study reported that costs were related to disease severity, increasing substantially in patients receiving a treatment with systemic effects. Higher costs can also be explained by a higher risk of mental health conditions, making patients recur to psychotherapy more often than non-patients. Other comorbidities, like thyroid disease, diabetes, and alopecia areata, also lead to more economic burden with drug and test costs [56]. Non-drug costs include the purchase of additional products, such as sunscreens, protective clothing, and cosmetic concealers, that exceed typical skincare expenditures, as well as transportation to therapy center costs. Transport costs could also be higher when other comorbidities are present since people with these conditions tend to have more medical visits, including emergency room outpatient and inpatient visits [55]. Indirect social costs refer to the time allocated to treatment. Patients invest considerable time in managing their condition, which can result in work absenteeism and reduced productivity, ultimately impacting their income. Additionally, the increased psychological distress in these patients could also lead to loss of work productivity because of therapy or disabling symptoms. [55, 56]

Given the limited number of studies addressing this topic, further investigation is needed to comprehensively evaluate the economic burden of vitiligo, since decisions regarding treatment options and the allocation of limited healthcare resources are heavily influenced by the evidence available. It is also essential for physicians to consider both the costs and benefits of available treatments and to engage in open discussions with patients, especially those from lower socio-

economic backgrounds, for whom financial barriers may lead to delayed treatment and, consequently, a further decline in QoL. [56]

Perceptions of vitiligo

Skin color significantly influences perceptions of an individual's health and value, particularly in cultures that place a profound significance on appearance and pigmentation. Any condition that alters one's appearance can lead to a loss of privilege and opportunities, limiting prospects for upward social mobility [57]. In certain cultures, such as India, vitiligo is often surrounded by derogatory terms and misconceptions, such as its supposed connection to leprosy, beliefs that it is contagious or hereditary, and deep-rooted superstitions. These factors contribute to considerable social stigma, leading to social exclusion, particularly affecting marriage prospects, as well as abuse and limited career opportunities. Research shows that women with vitiligo are particularly vulnerable, as their condition can significantly hinder their chances of marriage in traditional societies where skin appearance is heavily scrutinized. Additionally, the stigma associated with vitiligo may cause delays in diagnosis and treatment, as individuals may hesitate to seek help for fear of judgment. [16, 58, 59]

In cultures where darker skin tones are prevalent, vitiligo can be equated with leprosy in terms of its social repercussions, where patients can be considered as unclean [36]. Furthermore, misconceptions about vitiligo, such as the belief that it is caused by excessive sun exposure, often prevent individuals from seeking appropriate treatment. A Turkish survey found that 37% of vitiligo patients held this false belief, highlighting the need for healthcare providers to address and clarify misconceptions. By educating both patients and their families that vitiligo is neither contagious nor a personal fault, healthcare providers can help normalize the condition and reduce its emotional burden. [41]

Psychosocial burden

Skin, as the body's largest organ, plays an important role in our interaction with the world and in how we perceive both ourselves and others. In that sense, any condition that affects someone's appearance, such as skin color, can lead to psychological and social challenges. [8]

Thus, it is not surprising that the appearance of depigmented patches on the skin may provoke a range of complex emotional responses, such as nervousness, embarrassment, decreased self-confidence, anger, and even anxiety and depression. All in all, vitiligo affects a person's well-being across many areas of life, including emotional health, social relationships, and employment opportunities. [15]

Stigma and self-esteem

Stigma is a multi-layered construct involving (1) the identification and labeling a difference, (2) the association of that difference with negative stereotypes and (3) the establishment of a social divide between "us" and "them", leading to (4) loss of status and exclusion, with social and economic consequences. A recently proposed conceptual model of stigmatization in visible skin diseases identifies two dimensions: external stigmatization, pertaining to the discrimination of a group based on stereotypes and prejudices connected to a specific trait, and internal stigmatization, where individuals internalize these prejudices. Regardless of its form, the consequences are serious, with impaired QoL and an increased risk of anxiety and depressive disorders. [60, 61]

In contemporary Western societies, physical appearance has become a vital aspect of self-evaluation. This emphasis on physical looks is reinforced daily through popular culture and mass media, where a flawless appearance is seen as a benchmark of beauty. Additionally, individuals tend to compare themselves to others whom they perceive as more attractive. Such comparisons significantly influence how stigmatized individuals assess their own self-worth [48]. Patients with vitiligo frequently report concealing or disguising their condition, either through clothing or by avoiding situations that require exposure, in an attempt to enhance their appearance, reflecting significant self-consciousness. [39]

Ezzedine et al. explored the psychosocial effects of vitiligo, offering a broader view of how these individuals often face social stigma fueled by misconceptions and beauty ideals, contributing to low self-esteem, diminished confidence, concealing and social avoidance behavior [16, 32]. Patient testimonies have shown the negative impact of vitiligo on their careers, with loss of job opportunities and discrimination in the workplace, and on daily social interactions, regardless of age or race. Also, the societal bias imposed on them may foster negative self-perception, affecting how they view their place in society [34, 57]. Furthermore, questions about their patches, lingering stares and rudeness can lead to long-term feelings of embarrassment and shame regarding their appearance, causing many patients to gradually withdraw from social interactions. [15, 46]

Moreover, in certain cultural contexts, distinct norms and beauty standards further intensify the pressure to conform, deepening the marginalization [15]. Indian research found that all stigmatized patients had significantly impaired QoL, as they were faced with restrictions on work opportunities, visiting shops and schools, meeting new people, and participating in festivals and rituals. Patients also claimed they were less respected in the community and found it difficult to maintain a long-term relationship [46]. The influence of culture on stigma, particularly within South Asian communities, underscores the urgent need for culturally sensitive support systems designed to address these unique challenges. [15]

Depression and anxiety

The psychosocial implications of vitiligo extend to mental health, with significant concerns over their impact on QoL. Recent systematic reviews and meta-analyses emphasize the link between vitiligo and psychological comorbidities, particularly depressive and anxiety disorders. Ezzedine et al. reported prevalence rates ranging from 0.1% to 62.3% for depression and from 1.9% to 67.9% for anxiety, while Lai et al. found that approximately one-third of patients exhibited depressive symptoms, with up to one-quarter having clinical depression. [16, 62]

The presence of psychosocial comorbidity is associated with certain sociodemographic and clinical parameters. The psychological burden is higher particularly in female, young, single, and dark-skinned patients, especially with lesions located in visible or in genital areas, extended BSA affected and longer disease duration (≥ 5 years). We must take the sociocultural context into account when analyzing the prevalence of psychological comorbidity in different communities. For instance, the prevalence of depressive symptoms is reported to be 24% among Caucasian patients, whereas studies conducted in Asia, Africa, or the Middle East indicate a prevalence of 35%. This variation may stem from differences in study designs and measurement tools, as well as greater lesion visibility on darker skin types and different stigmatization experiences due to cultural and religious beliefs. [60]

Vitiligo is considered in literature as both a potential cause and a consequence of psychiatric disorders, such as depression. Neuroendocrine dysregulation, responsible for the development of depression, has been implicated as a potential mechanism for depigmentation in vitiligo. Notably, psychological stress has been identified as a trigger for pigment loss in up to 62.5% of vitiligo cases. In response to mental stress, the hypothalamic–pituitary–adrenal axis releases catecholamines that cause vasoconstriction, overproduction of oxygen radicals and, ultimately, destruction of melanocytes in the skin. [62]

The significance of these studies lies in pointing out the emotional burden of vitiligo, particularly how the visible nature of the condition increases the risk of anxiety and depression. By recognizing this association, the studies emphasize the need for interventions that tackle both the physical and emotional aspects of vitiligo, making holistic support for these patients imperative. [15, 62]

Psychological burden in Childhood

As children and adolescents experience vitiligo during their emotional development, its psychological impact can be profound and have a lasting effect on personal self-esteem. A survey involving pediatric patients and their families reported a decline in QoL with age, with over 90% of adolescents (15–17 years) being bothered by their condition compared to only half of younger children (0–14 years). [49]

Experiences of skin-related stigmatization play a significant role in this impact. A German study revealed that 93% of children had been approached or questioned by others, 45% had received derogatory comments, 22% had been bullied, and 22% felt embarrassed, sad, or self-conscious [63]. Lesions present multiple challenges, with affected children experiencing more difficulty in forming friendships, restricting participation in sports activities, and missing more school days compared to their peers without vitiligo. [8, 64]

Silverberg and Silverberg reported that QoL impairment was more pronounced in adolescents who developed vitiligo at age 10 or later, suggesting that disease onset during a stage of identity development, when appearance becomes an important aspect of one's sense of self, has a significant impact [49]. The emotional burden is especially high during the preteen years, when they are building social and academic confidence, and during adolescence, a period of identity development. In this group, self-consciousness emerged as the most affected area of QoL, suggesting that the emotional impact of vitiligo outweighs its functional consequences. [49, 64]

The psychosocial impact in this age group is also influenced by the extent and distribution of lesions. Acrofacial vitiligo, particularly in adolescents, is associated with greater distress, teasing, and bullying, highlighting that lesion visibility may have a more profound effect than overall disease extent [8, 49, 64]. Although camouflage methods, such as clothing or makeup, may reduce functional impairment, the emotional toll remains high due to self-awareness and fear of rejection. Moreover, notable differences were observed between the lesion locations that concerned younger children and those that concerned their parents. This might suggest that younger children may not yet feel self-conscious, despite being more vulnerable to teasing and bullying within the school environment. [49]

Additionally, caregivers are also often affected, with parents or caregivers reporting depression (26%) and anxiety (42%) [41]. These findings highlight the importance of assessing stigmatization and mental health in both pediatric patients and their families to help them cope with the condition and prevent long-term psychological comorbidity.

Sexual dysfunction and marital relationships

Sexuality is a central aspect of human life and an integral component of HRQoL, encompassing sexual identity, orientation, reproduction, and related behaviors. According to WHO, sexual health

refers to physical, emotional, mental, and social well-being in relation to sexuality and involves embracing a positive attitude towards intimate relationships. [65]

Skin conditions have a significant impact on sexual health, as they affect an individual's appearance, self-esteem and interpersonal relationships. Vitiligo, specifically, has been associated with negative effects on sexual relationships, with over a quarter of patients experiencing sexual dysfunction, according to a recent systematic review [16, 66-68]. Patients often report feelings of shame and fear of rejection when initiating new intimate relationships, potentially leading to sexual withdrawal. [68, 69]

Sexual dysfunction is more pronounced among women, affecting arousal, lubrication, orgasm, and overall sexual satisfaction, whereas men primarily report reduced orgasmic satisfaction. These gender differences may be due to more body image concerns among women, contributing to feelings of unattractiveness and embarrassment [67-69]. Genital involvement appears to exacerbate sexual dysfunction, as shown by Sarhan et al., who reported significantly impaired sexual function in female patients with genital lesions [68]. Other studies have similarly identified greater BSA involvement and genital lesions as predictors of sexual dysfunction, although some findings suggest that any form of vitiligo may impair female sexual function. [31, 66]

Vitiligo may negatively impact marital relationships, particularly among younger women, who often face greater difficulties in establishing or maintaining marriages after disease onset [47]. In certain cultures, vitiligo is perceived as a defect and may constitute grounds for divorce [1]. However, some studies report longer marriage durations among patients with vitiligo, suggesting that increased awareness and psychological counseling for patients and their partners may mitigate the psychosocial burden and enhance quality of life. [66-68]

Strategies to reduce distress

Alongside medical treatment, management strategies such as camouflage and cognitive behavioral therapy might improve patients' ability to cope with the condition, decreasing vitiligo-associated burden. [16, 31]

Camouflage is mentioned in guidelines as a pillar in supportive therapy. Dermatocosmetic products, such as creams, concealers, and fixing sprays are available on the market. Cosmetic camouflage has been studied in both men and women and found to significantly decrease DLQI scores, regardless of sex [34]. Camouflage may also be helpful in children, with data showing a reduction in CDLQI after the use of foundation on the affected areas [41]. Cosmetic camouflage gives newly diagnosed cases a protected window of time to accept and adapt without experiencing appearance-related anxiety. Based on these results, dermatologists should familiarize themselves with camouflage use and discuss it with their patients, especially in newly diagnosed cases. [34]

The psychological stress caused by the white patches should also be taken into consideration during treatment. Depressive disorders have been found to not only be caused by the onset of vitiligo, but to also worsen the severity of vitiligo [62]. In alignment, studies have assessed that patients seeking support groups usually have more severe vitiligo. The positive relation between perceived social support and a reduced incidence of depressive symptoms highlights the role of support from family/friends/organizations in aiding people to cope with the emotional toll [59]. Hence, to improve treatments' efficacy, physicians should consider inquiring about anxiety and depression symptoms and attempt to normalize them to open the door for further discussion and referral if needed. [41]

A correlation between higher education levels and a greater ability among patients to understand vitiligo rationally has been shown in research. Psychological intervention often begins by educating patients about the disease and its treatment, as improving their knowledge can reduce anxiety and fear while encouraging a more active approach to management [15]. Self-help organizations and support groups provide patients with the opportunity for mutual contact and should be recommended to those seeking guidance on the daily management of their condition [13]. Nevertheless, some individuals may refrain from seeking a formal diagnosis due to personal or cultural beliefs that see vitiligo as untreatable or as a consequence of their behavior. Therefore, awareness campaigns about vitiligo's underlying causes and treatment could contribute to the clarification of misconceptions and minimize stigmatization. [15, 60, 67]

Conclusion

Vitiligo exerts a major impact on patients' quality of life, attributed to how it manifests, its chronic and unpredictable course, lack of definitive treatment, and frequent association with other comorbidities. The depigmented lesions significantly impact multiple domains of everyday functioning, including participation in leisure activities, school life, professional opportunities, and the establishment of social relationships. This burden is particularly pronounced among women, who often face greater societal pressure regarding their appearance; younger individuals, who seek inclusion in social, emotional, and professional relationships; and darker-skinned patients, due to higher visibility of their lesions. The impact on these people's quality of life is especially pronounced when lesions are located in visible or genital areas, the extent of skin involvement is greater, and the disease duration is longer.

With physical appearance becoming a crucial factor for self-evaluation in contemporary societies, it is not surprising that patients with depigmented lesions seek to have a flawless appearance and to conform. Affected individuals often experience significant emotional distress related to their disfiguring lesions, including feelings of embarrassment, frustration, low self-esteem, anxiety, and depression. Furthermore, the disease may also lead to stigmatization and discrimination, negatively influencing interpersonal relationships, including marriage, particularly in traditional societies, where cultural norms shape perceptions of physical appearance. Experiences of stigmatization, such as teasing and bullying, especially play a significant role in the psychological burden during childhood and adolescence, critical phases for emotional and identity development, often leading to long-term impact on self-esteem and mental health. Unsatisfactory treatment results and unrealistic expectations also add to the burden felt by these patients. Additionally, vitiligo imposes a considerable economic burden due to the need for prolonged treatment, frequent medical consultations for vitiligo or comorbidities, and indirect costs related to reduced work productivity. Thus, vitiligo's influence extends far beyond its visible manifestations, imposing a profound psychosocial burden, and it should not be dismissed as a cosmetic concern.

To mitigate the impact on quality of life, it is essential for physicians to recognize and understand the challenges faced by patients with vitiligo. Quality of life should be assessed through screening questionnaires, which can help guide patients towards appropriate mental health care and assist in adopting strategies to accept and cope with their condition, such as camouflage techniques and group therapy. While several vitiligo-specific questionnaires have been developed, none have been fully validated and the DLQI remains the most widely used and recommended instrument. A validated vitiligo-specific tool, applicable across all genders, age groups, and ethnicities, is thus a pressing need. Additionally, providing education about the underlying causes of vitiligo can help clarify misconceptions and reduce stigma surrounding the condition. Raising awareness about the challenges faced by patients is crucial for fostering a better understanding of vitiligo, ensuring it is recognized as more than just a cosmetic condition.

References

1 - Bergqvist C, Ezzedine K. Vitiligo: A Review. Dermatology. 2020;236(6):571-592. doi:10.1159/000506103

2 - Alikhan A, Felsten LM, Daly M, Petronic-Rosic V. Vitiligo: a comprehensive overview Part I. Introduction, epidemiology, quality of life, diagnosis, differential diagnosis, associations, histopathology, etiology, and work-up. J Am Acad Dermatol. 2011;65(3):473-491. doi:10.1016/j.jaad.2010.11.061

3 - Bibeau K, Pandya AG, Ezzedine K, et al. Vitiligo prevalence and quality of life among adults in Europe, Japan and the USA. J Eur Acad Dermatol Venereol. 2022;36(10):1831-1844. doi:10.1111/jdv.18257

4 - Picardo M, Huggins RH, Jones H, Marino R, Ogunsola M, Seneschal J. The humanistic burden of vitiligo: a systematic literature review of quality-of-life outcomes. J Eur Acad Dermatol Venereol. 2022;36(9):1507-1523. doi:10.1111/jdv.18129

5 - HU, Zhonghui, WANG, Tao. Beyond skin white spots: vitiligo and associated comorbidities. Frontiers in Medicine, 2023, 10: 1072837.

6 - Boniface K, Seneschal J, Picardo M, Taïeb A. Vitiligo: Focus on Clinical Aspects, Immunopathogenesis, and Therapy. Clin Rev Allergy Immunol. 2018;54(1):52-67. doi:10.1007/s12016-017-8622-7

7 - Ezzedine K, Lim HW, Suzuki T, et al. Revised classification/nomenclature of vitiligo and related issues: the Vitiligo Global Issues Consensus Conference. Pigment Cell Melanoma Res. 2012;25(3):E1-E13. doi:10.1111/j.1755-148X.2012.00997.x

8 - Seneschal J. Clinical Features of Vitiligo and Social Impact on Quality of Life. Dermatol Pract Concept. 2023;13(4S2):e2023312S. doi:10.5826/dpc.1304S2a312S

9 - van Geel N, Speeckaert R, Taieb A, et al. Koebner's phenomenon in vitiligo: European position paper. Pigment Cell Melanoma Res. 2011;24(3):564-573. doi:10.1111/j.1755-148X.2011.00838.x

10 - Taïeb A, Picardo M; VETF Members. The definition and assessment of vitiligo: a consensus report of the Vitiligo European Task Force. Pigment Cell Res. 2007;20(1):27-35. doi:10.1111/j.1600-0749.2006.00355.x

11 - Narayan VS, Uitentuis SE, Luiten RM, Bekkenk MW, Wolkerstorfer A. Patients' perspective on current treatments and demand for novel treatments in vitiligo. J Eur Acad Dermatol Venereol. 2021;35(3):744-748. doi:10.1111/jdv.16927

12 - Wang X, Wu W, Chen J, Li C, Li S. Management of the refractory vitiligo patient: current therapeutic strategies and future options. Front Immunol. 2024;14:1294919. doi:10.3389/fimmu.2023.1294919

13 - Böhm M, Schunter JA, Fritz K, et al. S1 Guideline: Diagnosis and therapy of vitiligo. J Dtsch Dermatol Ges. 2022;20(3):365-378. doi:10.1111/ddg.14713

14 - Jafferany M, Pastolero P. Psychiatric and Psychological Impact of Chronic Skin Disease. Prim Care Companion CNS Disord. 2018;20(2):17nr02247. doi:10.4088/PCC.17nr02247

15 - Salama AH, Alnemr L, Khan AR, Alfakeer H, Aleem Z, Ali-Alkhateeb M. Unveiling the Unseen Struggles: A Comprehensive Review of Vitiligo's Psychological, Social, and Quality of Life Impacts. Cureus. 2023;15(9):e45030. doi:10.7759/cureus.45030

16 - Ezzedine K, Eleftheriadou V, Jones H, et al. Psychosocial Effects of Vitiligo: A Systematic Literature Review. Am J Clin Dermatol. 2021;22(6):757-774. doi:10.1007/s40257-021-00631-6

17 - Megari K. Quality of Life in Chronic Disease Patients. Health Psychol Res. 2013;1(3):e27. doi:10.4081/hpr.2013.e27

18 - Karimi M, Brazier J. Health, Health-Related Quality of Life, and Quality of Life: What is the Difference?. Pharmacoeconomics. 2016;34(7):645-649. doi:10.1007/s40273-016-0389-9

19 - Felce D, Perry J. Quality of life: its definition and measurement. Res Dev Disabil. 1995;16(1):51-74. doi:10.1016/0891-4222(94)00028-8

20 - Koller M, Klinkhammer-Schalke M, Lorenz W. Outcome and quality of life in medicine: a conceptual framework to put quality of life research into practice. Urol Oncol. 2005;23(3):186-192. doi:10.1016/j.urolonc.2005.03.002

21 - Cummins RA. Moving from the quality of life concept to a theory. J Intellect Disabil Res. 2005;49(Pt 10):699-706. doi:10.1111/j.1365-2788.2005.00738.x

22 - Yin S, Njai R, Barker L, Siegel PZ, Liao Y. Summarizing health-related quality of life (HRQOL): development and testing of a one-factor model. Popul Health Metr. 2016;14:22. doi:10.1186/s12963-016-0091-3

23 - Chernyshov PV, Tomas-Aragones L, Manolache L, et al. Quality of life measurement in vitiligo. Position statement of the European Academy of Dermatology and Venereology Task Force on Quality of Life and Patient Oriented Outcomes with external experts. J Eur Acad Dermatol Venereol. 2023;37(1):21-31. doi:10.1111/jdv.18593

24 - Fekete L, Iantovics LB, Fekete GL. Validation of the DLQI questionnaire in assessing the disease burden and principal aspects related to life quality of vitiligo patients. Front Psychol. 2024;15:1333723. doi:10.3389/fpsyg.2024.1333723

25 - Yang TT, Lee CH, Lan CE. Impact of Vitiligo on Life Quality of Patients: Assessment of Currently Available Tools. Int J Environ Res Public Health. 2022;19(22):14943. doi:10.3390/ijerph192214943

26 - Hedayat K, Karbakhsh M, Ghiasi M, et al. Quality of life in patients with vitiligo: a cross-sectional study based on Vitiligo Quality of Life index (VitiQoL). Health Qual Life Outcomes. 2016;14:86. doi:10.1186/s12955-016-0490-y

27 - Lilly E, Lu PD, Borovicka JH, et al. Development and validation of a vitiligo-specific quality-of-life instrument (VitiQoL). J Am Acad Dermatol. 2013;69(1):e11-e18. doi:10.1016/j.jaad.2012.01.038

28 - Maghfour J, Shoukfeh R, Hamzavi IH, Ezzedine K, Mohammad TF. Assessing the trends of outcome measures and quality of life instruments in vitiligo: A systematic review. J Eur Acad Dermatol Venereol. 2023;37(11):2270-2272. doi:10.1111/jdv.19419

29 - Salzes C, Abadie S, Seneschal J, et al. The Vitiligo Impact Patient Scale (VIPs): Development and Validation of a Vitiligo Burden Assessment Tool. J Invest Dermatol. 2016;136(1):52-58. doi:10.1038/JID.2015.398

30 - Catucci Boza J, Giongo N, Machado P, Horn R, Fabbrin A, Cestari T. Quality of Life Impairment in Children and Adults with Vitiligo: A Cross-Sectional Study Based on Dermatology-Specific and Disease-Specific Quality of Life Instruments. Dermatology. 2016;232(5):619-625. doi:10.1159/000448656

31 - Silverberg JI, Silverberg NB. Association between vitiligo extent and distribution and quality-of-life impairment. JAMA Dermatol. 2013;149(2):159-164. doi:10.1001/jamadermatol.2013.927

32 - Pandya AG, Amoloja T, Bibeau K, et al. Assessing Participants' Experiences with Vitiligo from Patient Interviews. Dermatol Ther (Heidelb). 2024;14(9):2467-2478. doi:10.1007/s13555-024-01241-w

33 - Rosmarin D, Soliman AM, Piercy J, Marwaha S, Anderson P, Camp HS. Health-Related Quality of Life Burden Among Adults with Vitiligo: Relationship to Disease Severity and Disease Location. Dermatol Ther (Heidelb). 2024;14(6):1633-1647. doi:10.1007/s13555-024-01187-z

34 - Bassiouny D, Hegazy R, Esmat S, et al. Cosmetic camouflage as an adjuvant to vitiligo therapies: Effect on quality of life. J Cosmet Dermatol. 2021;20(1):159-165. doi:10.1111/jocd.13459

35 - Ezzedine K, Seneschal J, Da Silva A, et al. Vitiligo patient population and disease burden in France: VIOLIN study results from the CONSTANCES cohort. J Eur Acad Dermatol Venereol. 2023;37(11):2249-2258. doi:10.1111/jdv.19447

36 - Amer AA, Gao XH. Quality of life in patients with vitiligo: an analysis of the dermatology life quality index outcome over the past two decades. Int J Dermatol. 2016;55(6):608-614. doi:10.1111/ijd.13198

37 - Awal G, Kaur N, Singh G, Sharma N. Impact of Vitiligo on Quality of Life in Patients of Skin of Color and Its Correlation With Clinical Severity Assessment Scores Utilizing Disease Specific Scores: A Cross-Sectional Study. Dermatol Pract Concept. 2024;14(2):e2024075. doi:10.5826/dpc.1402a75

38 - Radtke MA, Schäfer I, Gajur A, Langenbruch A, Augustin M. Willingness-to-pay and quality of life in patients with vitiligo. Br J Dermatol. 2009;161(1):134-139. doi:10.1111/j.1365-2133.2009.09091.x

39 - Ahmed A, Steed L, Burden-Teh E, et al. Identifying key components for a psychological intervention for people with vitiligo - a quantitative and qualitative study in the United Kingdom using web-based questionnaires of people with vitiligo and healthcare professionals. J Eur Acad Dermatol Venereol. 2018;32(12):2275-2283. doi:10.1111/jdv.15168

40 - Rosmarin D, Lofland JH, Marwaha S, Piercy J, Anderson P, Liu J. Patient Burden of Nonsegmental Vitiligo: A US Real-World Survey of Dermatologists and Their Patients. Dermatol Ther (Heidelb). 2024;14(6):1531-1546. doi:10.1007/s13555-024-01165-5

41 - Mahama AN, Haller CN, Ahmed AM. Psychosocial considerations in the management of vitiligo. Clin Dermatol. 2023;41(1):82-88. doi:10.1016/j.clindermatol.2023.02.008

42 - Dahir AM, Thomsen SF. Comorbidities in vitiligo: comprehensive review. Int J Dermatol. 2018;57(10):1157-1164. doi:10.1111/ijd.14055

43 - Sheth VM, Guo Y, Qureshi AA. Comorbidities associated with vitiligo: a ten-year retrospective study. Dermatology. 2013;227(4):311-315. doi:10.1159/000354607

44 – Alkhateeb A, Fain PR, Thody A, Bennett DC, Spritz RA. Epidemiology of vitiligo and associated autoimmune diseases in Caucasian probands and their families. Pigment Cell Res. 2003;16(3):208-214. doi:10.1034/j.1600-0749.2003.00032.x

45 - Gill L, Zarbo A, Isedeh P, Jacobsen G, Lim HW, Hamzavi I. Comorbid autoimmune diseases in patients with vitiligo: A cross-sectional study. J Am Acad Dermatol. 2016;74(2):295-302. doi:10.1016/j.jaad.2015.08.063

46 - Sawant NS, Vanjari NA, Khopkar U. Gender Differences in Depression, Coping, Stigma, and Quality of Life in Patients of Vitiligo. Dermatol Res Pract. 2019;2019:6879412. doi:10.1155/2019/6879412

47 - Wang KY, Wang KH, Zhang ZP. Health-related quality of life and marital quality of vitiligo patients in China. J Eur Acad Dermatol Venereol. 2011;25(4):429-435. doi:10.1111/j.1468-3083.2010.03808.x

48 - Sampogna F, Samela T, Abeni D, et al. A cross-sectional study on gender differences in body dysmorphic concerns in patients with skin conditions in relation to sociodemographic, clinical and psychological variables. J Eur Acad Dermatol Venereol. 2025;39(4):823-832. doi:10.1111/jdv.20247

49 - Silverberg JI, Silverberg NB. Quality of life impairment in children and adolescents with vitiligo. Pediatr Dermatol. 2014;31(3):309-318. doi:10.1111/pde.12226

50 - Kota RS, Vora RV, Varma JR, Kota SK, Patel TM, Ganjiwale J. Study on Assessment of Quality of Life and Depression in Patients of Vitiligo. Indian Dermatol Online J. 2019;10(2):153-157. doi:10.4103/idoj.IDOJ_14_18

51 - Ingordo V, Cazzaniga S, Medri M, et al. To what extent is quality of life impaired in vitiligo? A multicenter study on Italian patients using the dermatology life quality index. Dermatology. 2014;229(3):240-247. doi:10.1159/000363407

52 - Ezzedine K, Grimes PE, Meurant JM, et al. Living with vitiligo: results from a national survey indicate differences between skin phototypes. Br J Dermatol. 2015;173(2):607-609. doi:10.1111/bjd.13839

53 - Porter JR, Beuf AH. Racial variation in reaction to physical stigma: a study of degree of disturbance by vitiligo among black and white patients. J Health Soc Behav. 1991;32(2):192-204.

54 - Bae JM, Kim JE, Lee RW, et al. Beyond quality of life: A call for patients' own willingness to pay in chronic skin disease to assess psychosocial burden-A multicenter, cross-sectional, prospective survey. J Am Acad Dermatol. 2021;85(5):1321-1324. doi:10.1016/j.jaad.2020.09.088

55 - Naldi L, Pagani A, Alduini C. Vitiligo: Epidemiology and Economic Impact. Dermatol Pract Concept. 2023;13(4S2):e2023315S. doi:10.5826/dpc.1304S2a315S

56 - Ezzedine K, Soliman AM, Li C, Camp HS, Pandya AG. Economic Burden among Patients with Vitiligo in the United States: A Retrospective Database Claims Study. J Invest Dermatol. 2024;144(3):540-546.e1. doi:10.1016/j.jid.2023.08.025

57 - Grimes PE, Miller MM. Vitiligo: Patient stories, self-esteem, and the psychological burden of disease. Int J Womens Dermatol. 2018;4(1):32-37. doi:10.1016/j.ijwd.2017.11.005

58 - Akl J, Lee S, Ju HJ, et al. Estimating the burden of vitiligo: a systematic review and modelling study. Lancet Public Health. 2024;9(6):e386-e396. doi:10.1016/S2468-2667(24)00026-4

59 - Raheel MFS, Snoubar Y, Mosbah WS. Being female with vitiligo disease in traditional societies within North Africa. Biopsychosoc Med. 2024;18(1):1. doi:10.1186/s13030-024-00299-4

60 - Böhm M, Sommer R, Gieler U, et al. Vitiligo - a disease: A position paper on stigmatization, life quality impairment and psychosocial comorbidity. J Dtsch Dermatol Ges. 2024;22(10):1327-1335. doi:10.1111/ddg.15503

61- Germain N, Augustin M, François C, et al. Stigma in visible skin diseases - a literature review and development of a conceptual model. J Eur Acad Dermatol Venereol. 2021;35(7):1493-1504. doi:10.1111/jdv.17110

62 - Lai YC, Yew YW, Kennedy C, Schwartz RA. Vitiligo and depression: a systematic review and meta-analysis of observational studies. Br J Dermatol. 2017;177(3):708-718. doi:10.1111/bjd.15199

63 - Krüger C, Panske A, Schallreuter KU. Disease-related behavioral patterns and experiences affect quality of life in children and adolescents with vitiligo. Int J Dermatol. 2014;53(1):43-50. doi:10.1111/j.1365-4632.2012.05656.x

64 - Choi S, Kim DY, Whang SH, Lee JH, Hann SK, Shin YJ. Quality of life and psychological adaptation of Korean adolescents with vitiligo. J Eur Acad Dermatol Venereol. 2010;24(5):524-529. doi:10.1111/j.1468-3083.2009.03452.x

65 - World Health Organization. Sexual health (Internet). 2019. Disponível em: https://www.who.int/health-topics/sexual-health#tab=tab_2. Consultado pela última vez a 2024/05/02.

66 - Yucel D, Sener S, Turkmen D, Altunisik N, Sarac G, Cumurcu HB. Evaluation of the Dermatological Life Quality Index, sexual dysfunction and other psychiatric diseases in patients diagnosed with vitiligo with and without genital involvement. Clin Exp Dermatol. 2021;46(4):669-674. doi:10.1111/ced.14511

67 - Liang X, Guo F, Cai X, et al. Association between vitiligo and sexual dysfunction: current evidence. Ann Med. 2023;55(1):946-953. doi:10.1080/07853890.2023.2182906

68 - Sarhan D, Mohammed GF, Gomaa AH, Eyada MM. Female Genital Dialogues: Female Genital Self-Image, Sexual Dysfunction, and Quality of Life in Patients With Vitiligo With and Without Genital Affection. J Sex Marital Ther. 2016;42(3):267-276. doi:10.1080/0092623X.2015.1010678

69 - Sukan M, Maner F. The problems in sexual functions of vitiligo and chronic urticaria patients. J Sex Marital Ther. 2007;33(1):55-64. doi:10.1080/00926230600998482

INSTITUTO DE **CIÊNCIAS BIOMÉDICAS ABEL SALAZAR**

