

ABOUT THE AUTHOR



Vijay Sandhu, MD, FRCPC, DABD

Dr. Vijay Sandhu is board-certified in dermatology in both Canada and the United States. She is a graduate of the University of Toronto Medical School and Dermatology Residency Program, where she served as Co-Chief Resident. She practices community dermatology in Toronto, Canada. Her clinical interests include pigmentary disorders and immune mediated inflammatory diseases.

Affiliations: Elevate Dermatology, Toronto, ON

Beyond Depigmentation: Understanding the Psychosocial Burden of Vitiligo in a Canadian Context

Vijay Sandhu, MD, FRCPC, DABD

Introduction

Vitiligo is a common cutaneous autoimmune disorder presenting with depigmented patches of skin. It is often described in textbooks as a cosmetic disease, with disease manifestations confined to the skin. However, for many patients living with vitiligo, this characterization could not be further from the truth.

In recent years, the approval of ruxolitinib cream (Opzelura), a topical Janus kinase (JAK)1/2 inhibitor, has renewed clinical and research interest in vitiligo. Prior to this advancement, treatment options for the disease had remained limited. Coupled with this shift in management, emerging evidence highlights that the impact of vitiligo goes well beyond the skin. As new therapies emerge, a nuanced understanding of the disease's psychosocial impact is paramount

to informing dermatologic care, guiding equitable access to treatment, and shaping dermatologic policy within the Canadian context.

A Misunderstood Disease

Vitiligo affects approximately 1–2% of the world's population.¹ Historical reports of vitiligo date back more than 3,500 years.² However, despite its long-recognized existence, vitiligo remains misunderstood in some parts of the world, and is still mistaken for communicable diseases such as leprosy.³ Studies examining beliefs about vitiligo consistently identify common misconceptions, including the belief that vitiligo is contagious, results from a lack of hygiene, or is caused by external superstitious forces (e.g., the "evil eye", or sorcery). In some countries,

women with this disease can be prohibited from marriage, speaking to the substantial stigma that can surround this disease.³ In a country as culturally diverse as Canada, understanding how vitiligo is perceived across different communities, and the resulting social implications, is essential to delivering culturally competent dermatologic care.

A Highly Visible Disease

The presentation of vitiligo can be variable; however, two main patterns exist: segmental and non-segmental vitiligo.² Segmental vitiligo typically presents earlier in life, most commonly involving the face, and is often resistant to conventional therapies. In contrast, non-segmental vitiligo can manifest in both localized and generalized patterns. One notable variant, acrofacial vitiligo, predominantly affects highly visible and socially significant areas such as the hands and face. Disease involvement at these highly visible and socially significant sites further contributes to the burden of vitiligo. Facial involvement carries disproportionate social consequences, as the face is central to identity, communication, and social interaction. Multiple studies have shown that highly visible lesions are associated with a greater psychosocial burden and impaired quality-of-life.⁴ The development of the Facial Vitiligo Area Scoring Index (F-VASI) reflects the growing recognition of the importance of facial vitiligo as an important entity distinct from vitiligo affecting other body sites.

Not a One Size Fits All Disease

The psychosocial burden of vitiligo is not experienced uniformly; rather, it is intricately intertwined with existing cultural and social disparities. Several studies have consistently shown that individuals with higher Fitzpatrick skin types experience a disproportionately greater psychosocial impact from vitiligo.⁵ In individuals with more richly pigmented skin, disease visibility is accentuated further by the sharp contrast between depigmented lesions and surrounding skin, making lesions more visible and often more socially salient. This heightened visibility may contribute to the increased psychosocial burden

reported by those with higher Fitzpatrick skin types.⁴

In addition to the increased visibility of disease, pre-existing cultural stigmatization of vitiligo can further intensify the stigma of the disease. As reviewed above, many communities share beliefs about vitiligo that contribute to social and marital exclusion.³ For individuals with skin of colour, who may already face systemic social inequities, the added visibility of vitiligo can increase feelings of marginalization.

Stigmatization in Vitiligo

Stigma refers to social implications and discrimination that arise due to negative beliefs associated with a disease.⁶ Stigmatization is an important driver of the psychosocial impact experienced by individuals with vitiligo. In one study, 90% of patients reported being questioned about their disease or being subjected to unwanted approaches by strangers due to their disease.⁷ Although patients themselves understood that their disease is not contagious, this mistaken belief was held by friends and family, reinforcing social isolation.³ In some cultural contexts, vitiligo is perceived as a “serious disease” due to its potential impacts on marriage prospects or employment opportunities.³

Qualitative research among South Asian women with vitiligo living in Britain further illustrates how existing cultural norms can shape lived experience.⁸ In this study, all participants reported experiencing intrusive reactions and, in some cases, overt discrimination. Notably, some women with extensive depigmentation reported increased social acceptance when they were perceived as being of European descent, reflecting ongoing colourism and the sociocultural value placed on lighter skin in some communities. Conversely, other participants reported a loss of ethnic identity following complete depigmentation. These varied experiences to extensive depigmentation highlight the complexity of factors at play for patients living with severe disease or undergoing iatrogenic depigmentation. Such findings highlight the importance of dermatologists carefully assessing the possible motivations and

potential mental health outcomes for patients requesting depigmentation therapies.

Importantly, stigmatization is not limited to patients with darker skin types. In a separate study of White participants living with vitiligo, similar challenges in feeling “different” and stigmatization were reported, highlighting that these challenges span the spectrum of skin tones.⁹

In another study, those with higher levels of perceived stigmatization were independently associated with lower subjective well-being, reinforcing the central role of social stigma in shaping mental health outcomes.¹⁰ Over time, the external stigma may become internalized, leading individuals anticipate negative judgment and alter their behaviour accordingly. This internalization can manifest as avoidance of intimate relationships, social withdrawal, and occupational limitations.

The Mental Health Burden of Vitiligo

Studies have shown an association between vitiligo and adverse mental health outcomes, such as anxiety and depression. Meta-analyses have demonstrated that the odds of developing depression are 4.96–5.05 times higher in those living with vitiligo compared to those without the condition.¹¹ Clinical depression rates have been reported as high as 25%,¹¹ with similar proportions reporting suicidal ideation.¹²

Anxiety disorders are likewise more prevalent among those with vitiligo, with meta-analyses demonstrating rates of anxiety up to 6.14 times higher than those observed in control populations.¹³ Additional psychiatric disorders commonly reported in vitiligo populations include adjustment disorder, agoraphobia, and social anxiety.¹⁴ In a systemic review, psychosocial comorbidities were more prevalent in vitiligo compared to acne, alopecia areata, atopic dermatitis, and urticaria.⁴ Moreover, when compared to non-dermatologic disease, the mental health burden of vitiligo has been reported to be comparable to diseases such as chronic lung disease, arthritis, cancer, and congestive heart failure.¹⁵

Not surprisingly, disparities in mental health burden are also evident among those with vitiligo. Higher rates of depression and anxiety have been

reported among individuals from non-Caucasian backgrounds, particularly those with darker skin types and more visible disease.⁵

The global VALIANT study, which included 3,541 individuals with vitiligo, further reinforces the impact of vitiligo on mental health.⁵ In this study, 58.7% of participants reported anxiety and depression. Screening with the Patient Health Questionnaire (PHQ-9), a commonly used tool to screen and measure depression severity, revealed that 55% of participants had moderate to severe depressive symptoms. Higher prevalence rates were observed among participants in India, those with darker skin types, facial and hand involvement, and in those with body surface area involvement greater than 5%.

Additional factors associated with decreased quality-of-life included young age (particularly age less than 30 years), unmarried/single relationship status and longer disease duration.⁴ Collectively, these findings reinforce that although vitiligo is medically benign, its psychological burden can rival that of serious systemic illnesses.

Impact on Daily Functioning and Employment

The consequences of stigmatization and psychiatric comorbidity extend into functional domains, including employment and career advancement. In one study of adults with vitiligo, employed participants reported a mean work impairment of 35.6%.¹⁶ Facial involvement was associated with a greater impact on work-related decisions, further highlighting the burden of visible disease.

Data from the VALIANT study further highlighted the impact of vitiligo on employment, with 41.9% of respondents reporting that they believed they would have progressed further in their careers if they did not have vitiligo.⁵ A study from Brazil described workplace exclusion and reduced job opportunities among individuals with vitiligo,¹⁷ illustrating how visible skin disease may function as a social determinant of health.

Beyond employment, vitiligo frequently affects daily activities. In the VALIANT study, between 42.9% and 55.2% of participants reported that vitiligo affected their everyday lives.⁵

These effects included altered clothing choices, reluctance to shake hands, challenges with intimacy, and avoidance of social gatherings.

Gaps in Treatment and Resultant Coping Strategies

Despite the challenges faced by those living with vitiligo, treatment options have historically been limited until relatively recently. In a 2020 study, 94% of participants reported a need for new treatment options, and 49% of patients felt current therapies to be ineffective.¹⁸ These findings show substantial unmet treatment expectations among patients.

Moreover, a considerable proportion of patients with vitiligo do not receive ongoing care. One study showed that within the first year after diagnosis, 60.8% of newly diagnosed patients did not receive vitiligo-related treatment.¹⁹ This proportion increased to 82% in the subsequent year, suggesting progressive disengagement from active treatment. Whether this reflects a lack of treatment options, decreased patient confidence in treatment options, inadequate access to ongoing care, or insufficient follow-up remains unclear. Regardless, these findings demonstrate that many individuals with vitiligo navigate their disease without ongoing medical follow-up.

In the absence of consistently effective or accessible therapies, many individuals with vitiligo adopt coping strategies. Common approaches include concealing affected areas with clothing, cosmetic camouflage, altered body positioning, and avoidance of certain situations.⁷ While these strategies may provide short-term psychosocial relief, they may also reinforce internalized stigma and social withdrawal in those with vitiligo.

Collectively, these findings illustrate a critical point: when treatments options are perceived as inaccessible or inadequate, the burden of disease shifts from medical management to social adaptation. Therefore, addressing vitiligo requires dermatologists to not only expand and optimize our therapeutical arsenal, but also to promote sustained patient engagement and acknowledge the psychosocial dimensions of care inherent to this disease.

Tools to Score Vitiligo Severity: Measuring What Matters

The largely “asymptomatic” nature of vitiligo presents challenges in accurately quantifying its impact on quality-of-life. The Dermatology Quality of Life Index (DLQI) is a commonly used tool to ascertain quality-of-life data in dermatologic diseases. However, it includes items related to physical symptoms such as pruritis, which are not relevant in vitiligo. Using such questionnaires may underestimate the psychosocial burden of vitiligo in comparison to other diseases such as eczema or psoriasis. The development of vitiligo-specific scales can help to bridge this gap.²⁰ These tools include the Vitiligo Impact Scale (VIS)-22 and the Vitiligo Life Quality Index (VLQI). More recently, the Vitiligo Impact Patient Scale (VIPs) was developed to quantify vitiligo impairment according to skin phototypes, acknowledging that disease visibility and social impact may vary according to pigmentation.

Conclusion

Although vitiligo is often labelled as an “asymptomatic” condition, its impact is far from benign. Across diverse cultural contexts and skin types, the condition is associated with significant stigma, mental health burden, and impairments in daily life and employment. For dermatologists, providing comprehensive care must therefore extend beyond achieving repigmentation. Meaningful vitiligo management requires recognition of cultural context, assessing psychosocial impact, and proactively addressing mental health.

Correspondence

Vijay Sandhu, MD, FRCPC, DABD
Email: sandhu.vijayk@gmail.com

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