

# The Visibility of Vitiligo

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## Abstract

The world's perception of skin disease has significantly evolved in the last few decades, owing to the greater representation of individuals impacted by visible conditions in society. The shifting mindset towards greater diversity and body positivity in the media has allowed for enhanced awareness of the psychological and physical experiences of individuals living with dermatological disease. This article will explore the heterogeneity of lived experiences with Vitiligo and awareness's role in empowering impacted individuals to feel more comfortable in their skin.

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Individuals with Vitiligo develop depigmented patches of skin, with the face and arms being commonly affected.<sup>1</sup> The estimated global prevalence is between 0.5–2%, with equal rates in males and females and half of all cases developing before age 20.<sup>1–3</sup> The exact prevalence in Canada and Manitoba is assumed to be similar due to the lack of local epidemiological data.

Historically, many societies viewed Vitiligo as a 'curse.'<sup>4,5</sup> Communities in medieval Europe often mistook Vitiligo for leprosy, separating individuals with Vitiligo from the rest of society.<sup>5</sup> As medicine evolved, Vitiligo emerged as a separate entity, now known to be an autoimmune condition affecting melanocytes.<sup>3</sup> Melanocytes are the cells that produce the skin pigment molecule melanin.<sup>6,7</sup> In the pathogenesis of Vitiligo, melanocytes release chemoattractants in response to intracellular stressors.<sup>6</sup> These molecules then guide autoreactive cytotoxic T-cells to the melanocytes' location, eventually leading to localized cell destruction and depigmentation.<sup>6</sup>

Despite an increased understanding of the disease, Vitiligo is still associated with a considerable psychosocial burden, with more than 97% of patients reporting a significant impact on quality of life.<sup>4</sup> The effect on the quality of life includes a substantial increase in comorbid depression and low self-esteem, with more than 92% having experienced stigma due to their Vitiligo.<sup>3,4</sup> Factors associated with the increased psychosocial impact include body surface area (BSA) involvement <25% and genital involvement (depigmented patches of skin develop on external genitalia).<sup>4,8</sup> It is also associated

with increased psychosexual dysfunction and stigma.<sup>4,8</sup> Many impacted individuals fear intimate partners will perceive them as having an STI or other infectious disease.<sup>8</sup> A recent study revealed that genital involvement was associated with significant sexual dysfunction in 1541 adults with Vitiligo.<sup>8</sup> Women often experience a greater psychiatric burden as well.<sup>4</sup> One study found over 60% of females and 40% of males with Vitiligo had clinically significant depression.<sup>4</sup>

While many individuals impacted by Vitiligo have experienced distress due to their condition, the nature of this distress differs by skin type.<sup>9</sup> Individuals with darker skin (Fitzpatrick skin types IV–VI)<sup>1</sup> report more significant distress regarding the impact of physical appearance and sense of identity.<sup>9</sup> In comparison, individuals with lighter skin have reported greater concern about developing skin cancer due to the condition.<sup>9</sup> For many persons with darker skin, their physical appearance plays a vital role in their ability to self-identify with a particular ethnic group and not be seen as 'other' by their people.<sup>9,11</sup> This illustrates an important difference in the lived experience of Vitiligo for people with a darker skin type.

Many patients describe the loss of identity that comes with the depigmenting disorder that often entails questioning self-esteem and self-worth.<sup>12</sup> Women of colour living with Vitiligo often experience a compounded effect leading to more shame from the depigmentation, discrimination in marriage and perceived inadequacy secondary to societal expectations of beauty.<sup>3–5,9,12</sup> However, changes in societal beauty

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<sup>1</sup>Fitzpatrick skin types are categories of skin colour based on an individual's tendency to develop a tan or a burn when exposed to sunlight. Fitzpatrick type I is very fair skin that is most likely to burn, while type VI is dark skin that never burns and is least sensitive to change in response to sunlight. Fitzpatrick skin types I–III are considered lighter skin tones and types IV–VI represent darker skin tones.<sup>10</sup>

standards and increasing awareness of Vitiligo may slowly challenge this negative perception. The last few decades have witnessed an increase in the presence of not-for-profit organizations and social media campaigns that have brought individuals living with Vitiligo to the spotlight.<sup>13-15</sup> This has led to more young people embracing their skin changes from Vitiligo as part of their journey and beauty.<sup>13,16</sup>

A notable example is Canadian model Winnie Harlow, whose modelling career had embraced her Vitiligo as part of her identity despite initially struggling with the condition when she was first diagnosed as a child.<sup>16</sup> Other students bullied Winnie due to her skin looking different.<sup>16</sup> The negative perception from others played a tremendous impact on her mental well-being.<sup>16</sup> She has founded a new skincare brand 'Cay Skin' that celebrates the beauty of Vitiligo.<sup>13,16</sup>

The UK-based Vitiligo Society is an example of a not-for-profit organization established in 1985.<sup>14</sup> This global organization raises awareness through various forms, including Instagram, up-to-date information on disease management for patients and research.<sup>14</sup> The Instagram posts feature many individuals with Vitiligo and capture their daily challenges of living with a visible skin condition.<sup>17</sup> The organization takes a unique and philanthropic stance by selling merchandise, such as dolls with Vitiligo, that recognize the skin condition and provide funding for the organization and research efforts.<sup>14</sup> The organization also offers parents' school support packs' that contains information for schools to create supportive environments for kids with Vitiligo and allow them to feel seen by the world around them.<sup>14</sup> Physicians can also refer patients to these resources to connect with others experiencing the same changes.

Most of the adequately conducted research is not accessible to the general public or people living with Vitiligo because publications are written for a scientific audience with access through paid subscription libraries. These organizations act as bridges that make research accessible and allow individuals with the disease to understand their condition better and connect to others. Providing information to people living with Vitiligo empowers and assists individuals in explaining misconceptions about their disease.

The Vitiligo Society, the Vitiligo Research Foundation and other organizations are especially active on June 25th for World Vitiligo Day.<sup>14,16,18</sup> Global celebrations of this day reach millions across the globe with the hashtag #worldvitiligoday, in similar ways as other health-promoting hashtags such as #worldmentalhealthday.<sup>15,18</sup> These awareness campaigns have recently increased outreach to more ethnically diverse populations.<sup>15,18</sup> These populations have a greater proportion of people with richer skin tones who experience a greater impact on their sense of identity and physical appearance.<sup>15,18</sup> World Vitiligo Day has a significant online presence that functions as a platform for people living with the condition to share their stories and be seen with the 'flaws' on their skin.<sup>19</sup> The awareness through organizations and social media has allowed for

a narrative of change and greater acceptance of the condition for individuals impacted by Vitiligo. Individuals with the condition are no longer afraid to post online images of themselves without covering up their skin.<sup>17,19</sup>

Acceptance of Vitiligo as part of one's identity has led some people to choose not to pursue any disease-altering treatment and instead focus on loving the body that they have.<sup>13,16,19</sup> Common treatments for Vitiligo include steroid creams and light therapy that aim to pigment existing patches and slow down disease progression.<sup>20</sup> Most treatments for Vitiligo seek to conceal the depigmentation as much as possible.<sup>20</sup> The choice not to pursue therapy is an important decision that highlights an essential change in an individual's perception of the condition. This change has considerable consequences for the clinical setting and highlights that clinicians should not make assumptions about an individual's therapy goals.

Individuals living with the disease have given various TED talks over the past few years, highlighting everyone's unique journey.<sup>21,22</sup> Speakers have spoken about how embracing their Vitiligo as part of who they are and not something to be ashamed of has been liberating.<sup>21,22</sup> These platforms have allowed individuals living with Vitiligo to define their journey rather than medicine or outdated preconceptions. The sharing of these stories is essential for young people who are newly diagnosed with Vitiligo.

In summary, every individual's experience with the condition is as unique as the Vitiligo pattern on their skin. While many people living with it have unfortunately experienced distress and discrimination, the changing landscape of what society defines as beautiful allows for greater visibility and acceptance on both a personal and societal level. The emergence of advocacy organizations and social media awareness empowers individuals living with Vitiligo to share their stories as people with visible skin disease.

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