



Original Research

Vitiligo: Patient stories, self-esteem, and the psychological burden of disease ☆☆☆

P.E. Grimes, MD ^{a,b,*}, M.M. Miller, BS ^c^a Vitiligo & Pigmentation Institute of Southern California, Los Angeles, CA^b Division of Dermatology, David Geffen School of Medicine, University of California, Los Angeles, CA^c Keck School of Medicine, University of Southern California, Los Angeles, CA

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ABSTRACT

Vitiligo is a relatively common disorder that is characterized by depigmented patches of skin. Multiple studies characterize the overwhelming psychological burden that is experienced by many patients around the globe. This review examines personal patient stories and the impacts of age, culture, sex, race, and ethnicity in relationship to altered self-esteem and quality of life in patients who live with vitiligo.

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Introduction

Vitiligo is an acquired disorder of pigmentation that is characterized by depigmented patches of skin due to the loss of melanocytes. Depigmented patches may appear in a localized or very generalized distribution. Vitiligo affects 1 to 2% of the global population with an equal incidence in male and female patients and in all racial/ethnic groups (Grimes, 2016a). Multiple theories have been proposed regarding the pathogenesis of this disorder (Harris, 2017). Current data suggest that vitiligo results from the complex interplay of genetics, oxidative stress, and autoimmunity (Grimes, 2016a). Recent studies document the role of CD8 lymphocytes and the interferon- γ CXCL10 cytokine signaling pathway in mediating the destruction of melanocytes in patients with vitiligo (Harris, 2017).

Therapies for vitiligo address the stabilization of the disease as well as the repigmentation of depigmented patches. Therapies that affect disease progression include systemic steroid medications, oral mini-pulse corticosteroid therapy, minocycline, and methotrexate. First-line therapies for repigmentation include topical corticosteroid

medications, calcineurin inhibitors, and narrowband ultraviolet B phototherapy (Grimes, 2016b).

Many global cultures and societies place a profound significance on appearance, esthetics, and pigmentation. Any condition that affects appearance may be fraught with loss of privilege, opportunities, and often upward societal mobility (Grimes, 2008). Given the inherent visibility of skin disorders, self-esteem is often compromised. The feeling of being ugly or undesirable has been described in patients with a myriad of cutaneous diseases that range from acne to alopecia areata to vitiligo. Skin disorders that negatively alter appearance have the potential to affect an individual's career as well as personal and social interactions. This effect on self-esteem and perception of beauty transcends race, age, sex, and socioeconomic status. Societies that have a cultural preference for specific skin tones often perceive pigmentation as a passport to society, and perceived defects are often devastating (Grimes, 2008).

Multiple studies have documented the psychological devastation that is inflicted by vitiligo. The seminal study by Porter et al. (1979) documented the negative impact of vitiligo on patients' self-esteem. The authors reported that patients who had lower self-esteem coped poorly with the disease, but patients with higher self-esteem coped better. Subsequent global studies have consistently reported the negative impact of vitiligo on patients' self-esteem and quality of life (QoL). Vitiligo causes isolation, stigmatization, loss of self-esteem,

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* Corresponding Author.

E-mail address: peggrimesmd@aol.com (P.E. Grimes).

depression, and self-consciousness. Herein, we highlight several patients' personal experiences in coping with vitiligo and review the psychological impact of this traumatic disease.

Patient stories

Subject 1: 13-year-old Hispanic female patient (Skin Type IV)

I was about 6 years old when I found out I had vitiligo. At first, I didn't know what it was but I quickly learned. When I was growing up, I didn't care what I looked like. Then, I switched schools and I didn't know what kids at school would say or think of me. However, they quickly learned and they accepted me for me. They don't care what I look like, which makes me feel happy. When I'm not at school, I will have my moments when I start to cry and tell myself horrible things like "I'm ugly," "what did I do to deserve this," and "I'm a horrible person." I know my family loves me for me, but sometimes it doesn't feel like enough. Now that I'm entering my teen years, I've started to care more about my self-appearance and self-esteem. I don't feel pretty with my spots. Sometimes I wish I could go back to my younger self [who] didn't care. I look at pictures of myself without spots and say to myself, "Wow, I didn't remember what certain parts of my body looked like and now they look very different." I know my teen years will be very different and I will need to turn to my family and friends for support.

Subject 2: 50-year-old African-American male patient (Skin Type VI)

I knew it was going to be a problem when I just finished lunch with a friend and she said, "You have something on the side of your mouth." I was working at WABC TV in New York City as the entertainment reporter. I had gone to the MTV Awards. I saw Michael Jackson's performance on stage. Earlier in the week, I interviewed Whoopi Goldberg for a reprise of a one-woman show. I was 26, in the biggest city, at the biggest station, and on the top-rated newscast. AND THERE WASN'T ANY FOOD ON MY MOUTH! It was my skin.

I had been able to cover the small spots on my hands and scalp... and the one small spot just under my nose. But after eating, the corners of my mouth could not be hidden. I thought the life I had created was over. I didn't know how to react. And with time it got much worse. My Emmy Award winning face was gone. I was a splotchy mix of black and white. And I went through some stages: grief, fear, grief, anger, grief, and acceptance. And let me be clear. IT'S BEEN YEARS... of questioning, emotional struggle, and crazy looks but the truth is a little shocking. This disease has become my blessing.

My name is LT, and I am an entertainment reporter/host in Detroit. I travel the world covering entertainment. I am also thankful to be an advocate for people like me. And I don't just mean people whose skin changes so drastically people question if they should shake your hand or hug you. I mean people who are struggling to exist comfortably and lovingly in their own bodies.

Vitiligo can be a challenge but I have found support and guidance leading to pride for my skin. I have created a life of my own definition. And now, I can't imagine my journey any other way. I have become a more loving and compassionate man. I am embracing the stares and directing the attention, when appropriate, to positive ends.

How do I live with vitiligo? I LIVE! Oh, and by the way, I have vitiligo.

Subject 3: 62-year-old Caucasian female patient (Skin Type II)

Born with a bathing trunk melanocytic nevus, all my life I've been self-conscious about my skin. Finding a one-piece bathing suit to cover my flank, back, and right upper thigh wasn't possible, but I imagined that the patches of brown that peeked out didn't show. No such luck in locker rooms where, fully naked, I heard taunting as a child and gasps

as an adult. I preemptively warned medical professionals after hearing the question "Have you been beaten?" too many times.

But nothing prepared me for the white patches that suddenly emerged in my thirties and that now, in my sixties, cover large areas of my body and face. You would be wrong to assume that as a white woman, patches of nonpigmented skin aren't noticeable or that they don't provoke anguish. Perhaps if I were alabaster white, I'd feel differently, but I think not. To lose color is to be a pale reflection of one's former self, to lose vividness and vitality. Moreover, in my case, vitiligo is likely a result of my nevus, of my body killing its own melanocytes like Pac-Man scrambling to kill the ghosts before they kill him. In my twenties, I was told for the first time that my nevus could kill me. Vitiligo proves the point.

I know that vitiligo is a far greater cosmetic affliction for black and brown people. In fact, I feel guilty for complaining or becoming distressed when people say, "But I can't see it." Though often said with good intentions, such dismissals compound my distress because they gaslight me and incite guilt. Besides, it is noticeable. Ask the gastrointestinal doctor who pointed it out to his students when trying to figure out why I perforated my colon. Ask the cosmetician trying to sell me foundation not knowing which skin color she should match. I'm brave. I act like it's nothing, just as I learned to do with my nevus. Then I go home. And then I cry.

People with skin conditions and perhaps other autoimmune disorders often feel tremendous guilt. Have we caused our lesions because our emotions are intense, because we're angry, because we can't handle the normal stresses of life? Has it spread because we don't meditate or do yoga or eat enough kale? John Updike called psoriasis, a condition he hid for much of his life, a dermal sin to which he had to confess. Never mind that we control very little in our lives, our culture demands, indeed, runs on the illusion that we have control if only we would seize it.

Incurable and unpredictable, vitiligo could not have provided a more perfect spur to the anxiety and depressive disorders I've had to manage since childhood. My clothes can no longer hide my skin disease. My skin has become a living metaphor.

But meet me on the street tomorrow and you'll never know that I'm hopeless or hiding. Be a fly on the wall in my wonderful dermatologist's office and you'll hear me tearfully confess my dermal sins and, perhaps, decide to begin treatment anew. Because when your doctor has a great, big soul, you too might say to yourself, why not? Why not keep trying?

These stories are profound personal narratives of stigmatization, loss of self-esteem, emotional traumas, grief experiences, and coping strategies. They reflect and provide a cross-cultural, multi-ethnic, age, and sex perspective of the burden of disease (Figs. 1, 2, and 3).

Impact of sex, culture, and race/ethnicity

The impact of vitiligo on patients' QoL has been assessed in global populations, and the outcomes vary. However, most results substantiate the negative impact of the disease on patients' QoL (Table 1; Bae et al., 2017; Belhadjali et al., 2007; Bhandarkar and Kundu, 2012; Borimnejad et al., 2006; Boza et al., 2016; Chan et al., 2013; Elbuluk and Ezzedine, 2017; Ezzedine et al., 2015, 2015; Ingordo et al., 2014; Kiprono et al., 2013; Komen et al., 2015; Ongenae et al., 2005; Parsad et al., 2003; Radtke et al., 2009; Silverberg and Silverberg, 2013; Talsania et al., 2010; Teovska Mitrevska et al., 2012).

In a large study of 1541 patients, the authors evaluated the associations among vitiligo extent, distribution of disease, and QoL impairment. Vitiligo had indeed a negative impact on total Dermatology Life Quality Index (DLQI) scores. Scores were significantly associated with an affected body surface area (BSA) of greater than 25% and body parts affected (Silverberg and Silverberg, 2013). Eighteen percent of patients reported sexual dysfunction, with equal frequency in male and female patients, which correlated with the presence of genitalia lesions. In contrast, other studies have reported greater sexual dysfunction in female patients compared with male patients (Borimnejad et al., 2006). In an Italian population of 161 patients, although vitiligo

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