

PERSPECTIVE



The eye of the beholder

Clinicians and researchers must learn to talk about and treat vitiligo without alienating a growing chorus of patient advocates, says **John Harris**.

As a clinician–scientist who studies and treats the skin disease vitiligo, I am committed to improving the lives of my patients. The condition, which is characterized by white patches on the skin, results from the immune-mediated destruction of melanocytes — cells that produce melanin, the pigment that gives skin its colour. Vitiligo affects about one in every hundred people worldwide, without bias towards gender, race or geographic location. But it could be even more prevalent: many patients tell me that they hadn't sought clinical care previously (and therefore weren't included in official data) because they were unaware that treatment options exist.

At the clinic, I care for people who do seek treatment. In the laboratory, I work to better understand the mechanisms by which vitiligo arises and then progresses to develop potential treatments. And in the vitiligo community, I act as an advocate for patients to ensure that their treatment costs are covered, and to help reduce the stigma that is associated with the disease. Although these activities might seem synergistic, they have collided in unexpected ways. While my patients and millions of others around the world are clamouring for a cure, many so desperate that they go to great lengths to hide their symptoms, some people with the condition are demanding that it be accepted as part of everyday diversity. The clash could have a lasting effect on vitiligo research, funding and treatment.

The impact of vitiligo on a person's quality of life is comparable to that of skin conditions such as psoriasis and atopic dermatitis (eczema). Like those conditions, vitiligo is something that we should take seriously and seek to treat. But the condition is often overlooked by both clinicians and researchers, who dismiss it as being cosmetic. Vitiligo's impact and the care it demands is overwhelming, yet I battle daily with insurance companies to get treatment coverage for my patients, and with funding agencies to secure research support.

Depending on where they live, people with vitiligo can be admired for their stunning beauty or rejected for their shocking disfigurement. Many cultures attach a strong social stigma to the disease. One of my patients told me that on the flight he took to my clinic, the woman next to him asked to change seats because of the spots on his arms. In south Asia, and in India, in particular, vitiligo was once confused with the infectious disease leprosy, which is endemic in the region. Even today, India's culture of arranged marriage still ostracizes those who have vitiligo; not only those with the disease but also their siblings can be eliminated as marriage prospects. And in the United Kingdom, a man who was originally from Pakistan reportedly asked for advice on how to arrange amputation of part of his arm, which showed signs of vitiligo. He said that his family would accept him with just one arm, but not with the condition.

There is, however, an alternative narrative: one that hails the disease as something to be celebrated. Art exhibitions, advertisements and television shows feature models and actors with vitiligo, serving as an acclamation of the condition and the patterns that it imprints onto the skin of those affected. Some people even resist calling vitiligo a disease, possibly because the term subverts acceptance. Although this

body-positive standpoint seems to be that of a vocal minority, it receives the majority of media attention and helps to raise awareness of vitiligo worldwide. But it also creates a conflict, in which those who want to receive treatment feel undermined by those who do not, and vice versa. Similar dual narratives — in which seeking treatment or cosmetic solutions for a condition puts people at odds with others who accept it openly — exist in the albinism, dwarfism and deaf communities.

Such conflict is uncommon in other immune-mediated skin conditions. Some, including psoriasis and eczema, can be accompanied by discomfort in the form of itching or pain. But others, such as alopecia areata, typically are not, so this alternative perspective does not stem solely from lack of discomfort. And although only a limited number of treatments are available for vitiligo, many other diseases have even fewer effective therapies. The greater visibility of models and other individuals with vitiligo might have helped many in the community to embrace the

disease. But when singer Michael Jackson struggled publicly with vitiligo more than 20 years ago, he received a very different reception. Perhaps a combination of all these things, as well as cultural evolution, has created room for this perspective.

But no matter the reason, this second narrative has implications for the first. If vitiligo is beautiful, perhaps research on its treatment is unnecessary. Some might feel that people who seek care or feel devastated by their diagnoses imply that others, even those who accept it, should be ashamed of their appearance. Increased resistance to treatment and forced acceptance of the disease could impede the research effort.

Both perspectives are valid, healthy and appropriate. And although they seem to contradict each other, they confront the reality that

vitiligo cannot be ignored. As a clinician–scientist who has committed a considerable part of my career to treating and studying vitiligo, I straddle the line: I support patients who love their appearance and decline treatment and comfort those whose spots move them to tears.

The field is making progress. Clinicians are getting better at caring for people with vitiligo. Basic and translational research have provided insight into how vitiligo arises and real options for improved treatments, which are now being tested in clinical trials. Pharmaceutical companies have noticed that vitiligo represents an enormous, unmet clinical need.

Clinicians, researchers, patient advocates, people with vitiligo and their caregivers must set aside personal biases and seek to understand the effects that vitiligo has on all those it touches. Better yet, they should join the conversation. By working together, each of these groups can help people with vitiligo who feel alone and powerless, and empower those who call attention to the condition's unique beauty. There is now real hope for people with vitiligo, in terms of public acceptance of the condition and new, advanced treatments. And that is what's most important, no matter how you look at it. ■

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John Harris is director of the Vitiligo Clinic and Research Center at the University of Massachusetts Medical School in Worcester.
e-mail: john.harris@umassmed.edu