

BRIEF ARTICLE

Perspectives of Vitiligo Patients: Voices from National Vitiligo Conferences

Katie A. O'Connell, MD, MS¹, Ronnie M. Youssef, MD², Angeli Eloise Torres, MD³, Richard H. Huggins, MD³

¹ Department of Medicine, Vanderbilt University Medical Center, Nashville, TN

² Texas A&M Health Science Center, College of Medicine, Bryan, TX

³ Photomedicine and Photobiology Unit, Department of Dermatology, Henry Ford Health System, Detroit, MI

ABSTRACT

In the United States, many individual vitiligo support groups have collaborated on a joint national US World Vitiligo Day since 2016. As part of the 2020 and 2021 US World Vitiligo Day virtual events, polls were conducted that solicited information from participants regarding their life with vitiligo. A majority (76% in 2020; 92% in 2021) would like a cure for vitiligo. In 2020 and 2021, 40% and 35% responded they both show and hide their vitiligo when asked how they display their skin. A minority, 14% in 2020 and 5% in 2021, reported their vitiligo treatments were fully covered by their insurance. When polled about acceptance, in 2021, 40% reported they were accepting of their vitiligo most days. In 2021, 20% were interested in trying treatments, even if they included moderate side effects and 29% were interested, if minimal side effects. Results herein suggest that while many patients are accepting of their disease, many also want a cure. Additionally, dermatologists should advocate for coverage of vitiligo treatment, while also taking insurance coverage into account when discussing treatment options. Further, vitiligo patients require individualized care considering some patients may be open to attempting more aggressive treatment, despite the side effect profiles, while others are not interested in treatment or only willing to attempt treatments without side effects.

INTRODUCTION

Vitiligo is a chronic skin condition affecting 0.5 – 2% of the population that may result in psychosocial effects including shame, depression, anxiety, and stigmatization.¹ Patients with vitiligo report low quality of life (QOL) scores, which can be improved with the help of support groups, online communities, and dedicated research associations/societies. WVD is an annual global event which originated in Nigeria in

2011. WVD serves as a celebration of the vitiligo community with the goals of raising awareness about the condition and recognizing the hardships faced by individuals with vitiligo. In the United States, the many individual vitiligo support groups have collaborated on a joint national US World Vitiligo Day (US-WVD) since 2016.

METHODS

In both 2020 and 2021, US-WVD was held virtually, co-hosted by the Global Vitiligo Foundation and MyHealthTeams, a social network platform for patients with chronic conditions.² In total, 355 live viewers from 28 countries attended the 2020 US-WVD and 385 viewers from 27 countries attended the 2021 event. Participants during each event were surveyed about their vitiligo via live polling through the Zoom platform. Questions were asked at various timepoints throughout the programming of each event and were open for anonymous response from all live attendees. Thus, all live attendees were included and those who were not currently at their viewing device or watching a recording of the event were excluded. Survey questions were developed by a panel of dermatologists with a specific interest in vitiligo in conjunction with MyHealthTeams representatives specifically for use during virtual WVD. Five questions were asked in 2020 and seven questions were asked in 2021.

RESULTS

When asked, “do you want a cure for vitiligo?” 76% and 92% of respondents said they wanted a cure, while 24% and 8% said they did not in 2020 (N=70) and 2021 (N=39), respectively (**Table 1**). When asked whether they wanted to show off their vitiligo or hide it, 44% and 57% responded saying they show it off, 16% and 8% saying they hide it, and 40% and 35% saying they both show and hide it in 2020 (N=45) and 2021 (N=37), respectively. When asked if vitiligo treatments were covered by their insurance, 14% and 5% noted all were covered, 46% and 46% noted some were covered and 40% and 49% noted no treatments were covered in 2020 (N=50) and 2021 (N=37), respectively. In 2021, when asked how they feel about their vitiligo (N=87), 45% responded fully accepting most

days, 40% accepting some days, 8% not accepting most days, and 7% not accepting at all. In 2021, when asked if they were interested in trying treatments for vitiligo (N=82), 23% said yes, if no side effects, 29% replied yes, even if minimal side effects, 20% replied yes, even if moderate side effects, 14% responded no and 13% were not sure. Two questions regarding age and sunscreen usage are excluded from this report.

DISCUSSION

An overwhelming majority (76-92%) would like a cure for vitiligo and almost half are willing to try treatments with known side effects. Taken together, these underscore the profound impact vitiligo can have on patients’ QOL. Unfortunately, at this time there is only one Food and Drug Administration approved treatment for repigmentation of vitiligo lesions, ruxolitinib cream, approved in July of 2022.³ We clearly have significant unmet need with regard to treatment options for our vitiligo patient population. From the clinical side, considering the number of patients willing to attempt treatment despite potential side effects, physicians should educate themselves about the oral treatments that have evidence of effectiveness in vitiligo treatment and discuss escalation of therapy from topical to oral treatments for appropriate patients.

Insurance coverage for vitiligo treatments varies greatly despite robust data showing treatment efficacy in delaying disease progression.⁵ During the US-WVDs only a small number of those surveyed reported full insurance coverage for vitiligo treatment and, from 2020 to 2021 this number dropped even further. Lack of access to treatment as a result of insurance coverage and financial barriers potentially further exacerbates health

Table 1. Selected poll results from World Vitiligo Day 2020 and 2021.

Questions	% Responses (Total N)				
		Yes	No		
Do you want a cure for vitiligo?	2020 (N=70)	76	24		
	2021 (N=39)	92	8		
Do you show off your vitiligo or hide it?		Show	Hide	Both	
	2020 (N=45)	44	16	40	
	2021 (N=37)	57	8	35	
Are your vitiligo treatments covered by your health insurance?		All	Some	None	
	2020 (N=50)	14	46	40	
	2021 (N=37)	5	46	49	
How do you feel about your vitiligo?*(N=87)	Fully accepting most days	Accepting some days	Not accepting most days	Not accepting at all	
	45	40	8	7	
Are you interested in trying treatments for vitiligo?*(N=82)	Yes, if no side effects	Yes, even if minimal side effects	Yes, even if moderate side effects	No	Not sure
	23	29	20	14	13

*Poll Question asked at WVD-2021 only

disparities among the pediatric population and those with darker skin phototypes.⁵ Patient advocacy for individuals with vitiligo remains an essential part of caring for these patients. Clinicians must help continue the shift in the perception of vitiligo from that of a purely cosmetic condition to a true medical disease, particularly with respect to resistant insurance companies. In the meantime, clinicians should take insurance coverage into consideration when discussing treatment options with their patients.

Roughly half of surveyed individuals report no qualms about showing their vitiligo off, while the other half prefer to hide their vitiligo at least part of the time. Just under half of those surveyed feel fully accepting of their vitiligo most days, while a slight majority report struggling with their disease a significant proportion of the time. This is in line with the clear dichotomy between public/policymaker perceptions of supermodels proudly displaying their vitiligo on social media and individuals who feel uncomfortable in their appearance as a result of their vitiligo.⁶ Similarly, contrasting schools of thought exist within the vitiligo support community between those who advocate for a cure versus those who promote acceptance of the condition. It is useful for clinicians to take into consideration both viewpoints, as patients who belong to the latter may not be receptive to an aggressive treatment approach that would likely be more appealing to the former group. Ultimately, clinicians should be cognizant that no two vitiligo patients are alike and even the same individual's feelings towards their disease may change over time. Additionally, given that a majority of surveyed individuals hide their vitiligo at least part of the time and 15% of individuals surveyed generally do not feel accepting of their disease, clinicians should make sure to mention camouflaging options to their patients.

Limitations of this study include small sample size and variable response rates. Given that survey questions were asked to all attendees anonymously via live programming, it is possible that responses may have come from individuals not currently living with vitiligo.

CONCLUSION

US-WVD provided an invaluable opportunity for us to learn from our vitiligo patients. They reminded us that, while many patients are accepting of their disease, many patients also want a cure. When encountering a vitiligo patient whose disease is progressing despite topical therapy, providers should individualize care and bear in mind that some patients may be open to attempting oral therapy despite the side effect profiles. Additionally, providers should advocate for coverage of vitiligo treatment, while also taking insurance coverage into account when discussing treatment options. By paying attention to what vitiligo patients are telling us, we can better partner with them to help them achieve their individual and collective therapeutic goal.

Conflict of Interest Disclosures: KAO, RMY, and AET have no relevant disclosures. RHH is an investigator for Pfizer, Incyte, Arcutis and the Immune Tolerance Network.

Funding: None

Corresponding Author:

Richard H. Huggins, MD
Department of Dermatology, Henry Ford Medical Center – New Center One, 3031 West Grand Boulevard, Suite 800, Detroit, Michigan 48202
Phone: (800) 436-7936
Email: rhuggin1@hfhs.org

References:

1. Ezzedine K, Eleftheriadou V, Whitton M, van Geel N. Vitiligo. *Lancet*. 2015 Jul 4;386(9988):74-84. doi: 10.1016/S0140-

- 6736(14)60763-7. Epub 2015 Jan 15. PMID: 25596811.
2. My Health Teams. My Vitiligo Team [Internet]. Cited 2022 February 1. Available from: <https://www.myvitiligoteam.com>
 3. US Food and Drug Administration. FDA approves topical treatment addressing repigmentation in vitiligo in patients aged 12 and older [Internet]. 2022 July 19 [cited 2022 September 15]. Available from: <https://www.fda.gov/drugs/news-events-human-drugs/fda-approves-topical-treatment-addressing-repigmentation-vitiligo-patients-aged-12-and-older>
 4. Searle T, Al-Niaimi F, Ali FR. Vitiligo: an update on systemic treatments. Clin Exp Dermatol. 2021 Mar;46(2):248-258. doi: 10.1111/ced.14435. Epub 2020 Dec 22. PMID: 33350506.
 5. Blundell A, Sachar M, Gabel CK, Bercovitch LG. The scope of health insurance coverage of vitiligo treatments in the United States: Implications for health care outcomes and disparities in children of color. Pediatr Dermatol. 2021 Nov;38 Suppl 2:79-85. doi: 10.1111/pde.14714. Epub 2021 Jul 16. PMID: 34272764.
 6. Harris J. Vitiligo gets even more visibility: Chantelle Brown-Young on America's Next Top Model [Internet]. 2014 August 6 [cited 2022 March 10]. Available from: <https://www.umassmed.edu/es/vitiligo/blog/blog-posts1/2014/08/vitiligo-gets-even-more-visibility-chantelle-brown-young-on-americas-next-top-model/>